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**A Comparative Study of Carers
of Older People with Dementia in Scotland and Korea**

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Ph.D.

The University of Edinburgh

2011

To parents

DECLARATION

I declare that this thesis is of my own composition, based on my own work, with acknowledgement of other sources, and has not been submitted for any other degree or professional qualification.

HYUNSOOK LEE

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ABSTRACT

This study aims to explore Scottish and Korean carers' attitudes towards the diagnosis of dementia in their relative, family care, community care and to residential care in Scotland and Korea respectively, also under examination was the origin of different carers' attitudes between Scotland and Korea.

The dominant argument between previous Western and Eastern comparative studies on attitudes, has been that culture made the difference. In other words, the cultural factor was recognised as a main determinant of attitudes towards a diagnosis of dementia, towards social services at home and residential care in Asian societies, including Korea. This thesis starts with the question: Does culture really explain the phenomenon of Asian people's attitudes towards dementia? Indeed the tradition of filial piety has been changing and now seems to be rather weak in modern Asian society. In particular, contemporary Korea is modernised and westernised, as a result, many older people live apart from their adult children and their nuclear families.

This study asserts that Confucianism is a much less significant factor than differences in social policy. In other words, this thesis focuses not on Confucianism, but on the impact of institutions on carers' attitudes towards dementia. Finally, this thesis explores this argument through the following research question: What are the origins of different carers' attitudes between Scotland and Korea? In order to develop this argument, this thesis has carried out interviews with 14 Scottish carers and 28 Korean carers; and adopted a qualitative approach that would yield a rich exploration and deeper understanding of the different attitudes between carers in Scotland and Korea.

Based on this data, this thesis examines carers' attitudes towards the diagnosis of dementia (chapter 3), family care (chapter 4), community care (chapter 5), and residential care (chapter 6). Each

chapter analyses similarities and differences in attitudes in Scotland and Korea from the point of view of culture or the social welfare system.

To conclude, these findings explain that the origin of carers' attitudes in this study is based on social policy rather than culture. In other words, the Korean carers' attitudes and behaviours towards diagnosis and long-term care services are rooted in the residual welfare system rather than Confucianism. Likewise, this study found that Confucianism has a less significant influence than social policy on carers' attitudes towards the utilisation of health care, community care and residential care. Unlike previous studies on East Asia, that argue for a cultural explanation, this study of Korean carers demonstrates that the residual welfare system is more persuasive than the cultural approach derived from Confucianism .

This study contributes to the comparative study of Scotland and Korea as well as being a qualitative study in Korea. In addition, it will provide a new perspective on attitudes towards studies on East Asia. Moreover, the study will suggest political implications through the exploration of the carers' attitudes towards dementia diagnosis, social services at home and residential care. It also can provide lessons on dementia and dementia care from different experiences in Scotland and Korea.

Keywords: family carers, dementia, institution, culture, diagnosis, community care, residential care

List of Abbreviations

ADLs	Activities of Daily Living
DH	Department of Health
DWP	Department of Work and Pension
KIHASA	Korea Institute for Health and Social Affairs
LTCI	Long-Term Care Insurance
MA	Medical Aid
MHW	Ministry of Health and Welfare
MHWFA	Ministry of Health, Welfare and Family Affairs
NA	National Assistant
NBLS	National Basic Livelihood Security
NHI	National Health Insurance
NHIC	National Health Insurance Co-operation
NHS	National Health Service
VOCAL	the Voice Of Carers Across Lothian

Chapter 1. Introduction

1.1 Motivation and Purpose

My personal experience and academic interests motivated me to write this thesis. My experience of volunteer work in a nursing home in Edinburgh led to my study on dementia. Based on the Korean situation, my preconception about people in residential care in Scotland was that they were older people without family, neglected by their families, or very poor. In this vein, I considered that the residents must be isolated from society and would be unhappy. In other words, the families who left their parents in residential care homes would be somehow selfish or unethical.

Contrary to my expectations, I found in participant observation in Scotland that the relationship between residents and their families seemed to be very intimate and the quality of their life and their levels of satisfaction high. Sufferers' families visited them often and some family members even did voluntary work in the care home. On the question of why they decided to use care homes for their relatives, the most common answer was as follows: they thought that using care homes for their relatives with dementia was natural. In this context, they said that they would also use care homes when their

condition worsened. Another common answer was that the facility was located a stone's throw away from their homes. A carer said, "my mum just moved next to my house". In general, the attitude toward care homes and using them is very positive in Scotland.

Now it is time to examine the Korean case regarding attitudes towards and the use of care homes. It is likely that Koreans would not want to use the facilities because of Confucianism.

Confucianism emphasizes loyalty, filial piety, paternal benevolence or gender role, respect for elders, conflict avoidance and family values before the individual (Goodman and Peng, 2006). These moral norms were strong throughout the Yi dynasty (1392-1910) in Korea. Confucianism in this study means familialism, especially focusing on filial piety. The latter has been essential in governing the relationships between adult children and parents under Confucianism. It means that individuals are expected to have responsibility and obligation towards the family (Cho, 2000: 340).

On the other hand, according to newspapers and the true stories of carers of older people with dementia in Korea, many of the carers suffer from depression, strain, physical violence, abuse and fear for their lives and most people desperately want to use care homes. Yet, it is difficult to use them because the fees for the facilities are very high, except for those families entitled to use the 'National Basic Livelihood Security (hereafter NBLS) System', the social assistance system in Korea. In addition, some people have a negative attitude

towards care homes because of negative information regarding them, Confucian tradition, or the criticisms of other people. As can be seen above, Koreans have had a negative perspective on the use of care homes, despite having a desire to use care homes.

Accordingly, the attitude towards care homes is different in South Korea and Scotland. It is natural that this difference casts doubt and raises one question: ‘why do attitudes towards residential care differ so greatly in Scotland and Korea?’

Another motivation of this study lies in academic interests. First of all, it is necessary to answer how Korea, experiencing the fastest population ageing in the world, will deal with the problems of the aged and of caring. Korea has experienced “rapid ageing”. It is expected that Korea faces an ageing society, an aged society, and a super aged society in 2000, 2018, and 2026 respectively. In this vein, there has been growing interest in social policy for older people in Korea. For an in-depth understanding, a comparative social policy study has been suggested. For example, Scotland has experienced population ageing and established free personal and nursing care as a long-term care service. Consequently, this study starts to get insights from the comparative social policy for Korea on rapid ageing.

Secondly, my academic interest is because of the characteristics of dementia as a complex social problem. Older people with dementia face family, health, poverty, housing and social care problems. In this context, it is not too much to say that older people

are exposed to all kinds of social risk. Therefore, it is important to study the case of dementia (further discussion in next section). Moreover, dementia is characterised as a disease with a mental and physical problem. The attitudes of family carers to dementia are very important because the carers provide not only care, but also take all decisions for older people with dementia (see chapter 2). Thus, this study centres on the attitudes of carers towards older people with dementia.

Last but not least, the lack of studies on dementia carers' attitudes was another motivation to do this study. There is no comparative study between Scotland and Korea, while there are less qualitative studies and more quantitative studies on carers of older people with dementia in Korea. For a more in-depth understanding, this study will be based on the qualitative method. Also, previous studies have been based on cultural views about East Asian countries, while an institutional approach has been dominant in the west (see chapter 2). Therefore, this study will provide this academic area with a new explanation.

Based on the above motivations, the purposes of this study are:

- To examine carers' attitudes towards the diagnosis of dementia, social services at home and residential care in Scotland and Korea.

- To investigate the origin of different attitudes towards the diagnosis of dementia, social services and residential care in Scotland and Korea.

This study can contribute to a comparative study between Scotland and Korea and a qualitative study in Korea. In addition, it will provide a new perspective on attitudes towards studies on East Asia. Moreover, the study will suggest political implications through the exploration of the carers' attitudes towards dementia diagnosis, social services at home and residential care. It can also provide lessons on dementia and dementia care from different experiences in Scotland and Korea.

1.2 Dementia and Comparative Social Policy Study

Dementia as an important issue: Population, Attitude and Dementia Care

This study focuses on dementia because of the ageing population, different attitudes towards dementia and the difficulty of care for those with dementia.

The proportion of the older population with dementia is rapidly increasing. Korea and Scotland are already regarded as ageing societies, with over 7 per cent of people aged 65 and over.

In Scotland, the ageing of the population will continue over the next few decades (Anderson, 2004). Moreover, the number of older people aged 65 or over and the number of very old people aged 75 and over will increase rapidly over the next 10 years. According to the General Register Office for Scotland (2008), low fertility rate, and in particular the fertility rate in the generation of baby boomers, is the main reason behind the ageing population. In addition, 'life expectancy at birth for Scotland has improved from 71.9 years to 74.2 years for males and 77.5 years to 79.2 years for females, from 1993-1995 to 2003-2005 (General Register Office for Scotland, 2006). The Scottish population of pensionable age¹ and over was about 20 per cent of the total population in 2008. The number of people aged 65 and over was estimated to be 856,543 (16.6%) and people aged 75 and over was estimated to be 393,179 (7.6 %) in 2008 (see table1-1).

¹ Pensionable age is 65 for men, 60 for women until 2010; between 2010 and 2020 the pensionable age for women increases to 65. Between 2024 and 2026 the pensionable age for both men and women increases to 66 and changes again, in two further steps, to 68 by 2046 (General Register office for Scotland, 2007).

Table 1- 1 Scotland age structure in 2008

	Persons	Males	Females
All aged under 16	913,534	467,572	445,962
All aged under 18	1,045,693	535,335	510,358
All aged 16 & over	4,254,966	2,032,633	2,222,333
All aged 18 & over	4,122,807	1,964,870	2,157,937
All aged 16-29	952,991	485,346	467,645
All aged 30-44	1,065,187	514,781	550,406
All aged 45-59	1,067,863	519,667	548,196
All aged 60-64	312,382	151,994	160,388
All aged 65 & over	856,543	360,845	495,698
All aged 75 & over	393,179	147,476	245,703
Total	5,168,500	2,500,205	2,668,295

Source: General Register Office for Scotland, 2009.

In Scotland, there are at least 6 per cent of people over 65 affected by dementia (The Scottish Government, 2008). Alzheimer Scotland estimates that 69,500 people have dementia in Scotland and the number of people under the age of 65 was approximately 2,300 in 2009. The total number of people with dementia may increase to 127,000 by 2031 (Alzheimer Scotland, 2009). In Edinburgh, 5,921 people over the age of 65 were affected by dementia in 2009 (ibid.).

The rate of Korean population ageing is estimated as the fastest in the industrialised countries. Incidentally, the estimated number of people aged 70 and over (older old) and 80 and over (oldest old) shows rapid growth from 2005 to 2050.

**Table 1- 2 Estimated year of ageing society and Population of older people
Year from ageing society to super aged society**

	Year			Period in Years	
	Ageing Society	Aged Society	Super-aged Society	7→14%	14→20%
Japan	1970	1994	2006	24	12
France	1864	1979	2018	115	39
UK	1929	1976	2026	47	50
US	1942	2015	2036	73	21
Korea	2000	2018	2026	18	8

Source: e-national index, 2005. Ageing (7%), Aged (14%), Super aged (20%)

Increase in elderly population (Thousand persons) in Korea

Year	Total	Number of People			%		
		65+	70+	80+	65+	70+	80+
2005	48,294	4,383	2,686	678	9.1	5.6	1.4
2010	49,220	5,354	3,557	969	10.9	7.2	2.0
2018	49,934	7,162	4,870	1,689	14.3	9.8	3.4
2020	49,956	7,821	5,231	1,877	15.7	10.5	3.8
2026	49,771	10,357	6,687	2,333	20.8	13.4	4.7
2030	49,329	11,899	8,140	2,711	24.1	16.5	5.5
2050	42,348	15,793	12,344	5,859	37.3	29.1	13.8

Source: Kosis, 2005; cited from Choi, Won Young (2006).

Korea has an enforced childbirth control policy. The Five-year Plan for Economic Development from 1961 to 1995 decided to reduce the fertility rate. It materialised as a two child policy at the beginning, then a one child policy at the end. Since then, the fertility rate has decreased, whereas the number of people aged 65 and over has rapidly increased. Likewise, there has been a rapid increase in the number of the population aged over 65 in Korea, as can be seen in the fact that it takes 18 years from ageing to an aged society. According to the speed of ageing in Korea, the number of older people with dementia is expected to rise dramatically. The number of people with dementia is expected to increase from 218,096 to 619,132 people between 1995 and 2020. The estimated proportion of older people with dementia

will rise from 8.3 in 1995 to 9.0 in 2020. In 2010, at least 8.6 per cent of people aged 65 or over will have dementia.

Table 1- 3 Estimated number of older people with dementia (in persons)

	1995	2005	2010	2015	2020
Population aged 65 year and over	2,640,205	4,252,919	5,032,146	5,846,461	6,899,269
Number of older people with dementia	218,096	351,025	433,918	527,068	619,132
Age 65 ~ 69	23,744	36,606	38,161	43,413	53,400
70 ~ 74	35,298	54,274	65,977	69,023	78,892
75 ~ 79	62,068	100,328	128,396	155,367	162,292
80 & over	96,986	159,817	201,383	259,264	324,547
Estimated Rate (%) ¹⁾	8.3	8.3	8.6	9.0	9.0

Source : Korea Institute for Health and Social Affairs, Study on Development of Mapping in Dementia Management, 1997; KOSIS, 2009.

Note : 1) Number of older people with dementia per 100 older persons

Public opinion on community care in Scotland (2002) shows different attitudes toward older people with dementia and frail older people. People dislike older people with dementia as a neighbour, but most Scottish people would not mind living next door to a frail 90 year old (Curtice & Petch, 2002). Moreover, people feel that residential care is suitable for older people with dementia but not for frail older people (ibid.).

Caring for a person with dementia is probably regarded as the most difficult work because it might affect employment, household and personal finances, emotional health, and social and family life (Parker, 1997: 121). Some commentators have asserted that it is much harder than caring for a child with a mental disability (Whittick, 1985). Moreover, the family carers of older people with dementia have more serious depression than the family carers of old people who have had a

stroke (Silliman & Stenberg, 1988). Levin et al. (1989) pointed out that when family caregivers used residential care, 'the supporters on the whole experienced relief from work and worry on their relatives' entry into residential care and as a result most found their lives a lot easier than before' (p. 172).

Furthermore, they occasionally face threats to their life or health because the older person with dementia may have wild, florid behaviour symptoms. For example, Mr. K (Woo, 1997) became uncontrollable when he developed dementia, and tried to stab his family with a knife. Mrs. L with dementia (Family with Dementia Organisation, 2006) lived with her son and two grandchildren. She started a fire in her house when her son went on a business trip in which she and her two grandchildren died. Moreover, Mr. C, aged 60, cared for his mother who contracted dementia. He killed himself and his mother due to the difficulties of caring for his mother and financial problems (Yunhap news, 2005). Unlike the case of Mr. K whose family could afford the fee of a care home, many Korean families cannot pay the costs of a care home. Caring for sufferers isolates carers from friends and society and caused depression.

As described, caring for older people with dementia should be regarded as a complicated social problem rather than a personal family issue. In this vein, how countries understand and correct The Rev. Mary Webster pond with dementia depends on their level of social civilisation. Esping-Anderson (1999) pointed out that 'where the state

absorbs risks, the satisfaction of need is both ‘defamilialised’ (taken out of the family) and ‘de-commodified’ (taken out of the market) (1999:40). In this context, dementia care is a barometer for assessing social welfare in a society and state in terms of defamilialisation or decommodification.

Grounds for a Comparative Study

Previous dementia studies have mainly conducted research within a nation in order to measure the needs of dementia and evaluate social policies. In recent years the studies have been expanded to include comparative studies. These have given valuable insights into the similarities and differences among countries.

As described, the rationale for comparison can be found in the similar and different factors between Scotland and Korea. Common factors are an ageing population, similar philosophies, direction of social policy and increase interest in long-term care, especially for dementia. Different aspects include social culture, history of social welfare and the social welfare systems.

In detail, there are some points in common between Scotland and Korea. Firstly, Scotland and Korea have similarities in their ageing populations, reasons for these ageing populations and a rise in the dementia population, although there are slight differences.²

² For example, Scotland faced an aging population earlier than Korea but the aging population in Korea is increasing faster than in Scotland.

Scotland and Korea are ageing societies. The Scottish population aged 65 and over was 16.6 per cent of the total in 2008, while the Korean population in the same category will be 11.0 per cent and 14 per cent in 2010 and in 2018 respectively. It is expected that a Super Aged Society in the UK and Korea will be reached in the same year, 2026. The main reasons why an ageing population has occurred in the two countries are also similar: low fertility rate and a rise in life expectancy. In addition, the number of people with dementia is increasing and maintaining this trend in Scotland and Korea.

Secondly, similarities can also be found in philosophies and the direction of social policies. Social welfare has been organised according to similar welfare philosophies in Scotland and Korea. In Britain, the Third Way as a basic philosophy emphasises ‘welfare to work’. Similarly, in Korea, ‘productive welfarism’ and ‘participatory welfare’ were introduced by the Kim Dae-Jung and the Roh Moo-Hyun governments. These welfare philosophies of Korea have been much inspired by the Third Way.

Based on these perspectives, Korea and Scotland have emphasised community care. The Third Way originated in Thatcherism. Thatcher’s government emphasised community care in order to retrench the finances of the National Health Service (hereafter NHS). Thatcher’s government reconstructed social policy based on ‘neo-liberalism’ in order to achieve its key goal, to ‘roll back the frontiers of the state’ and ‘end the culture of dependency’ (Wikeley &

Ogus, 2002: 6). The Conservative government insisted on care in the community rather than institutional care in order to reduce public expenditure and the state's role. In this context, the Korean government has also carried out social policy based on community care since the financial crisis in late 1997.

Thirdly, social services for older people with dementia have been neglected for a long time in Scotland and Korea, for different reasons. In Scotland, dementia has been dealt with from a medical perspective, thus dementia and dementia care have mainly been managed by the NHS. In addition, there is a low development of social policy for dementia and dementia care because of a weak political lobby. According to Innes (2002), 'dementia and dementia care have historically occupied a low position on the political agenda, and there has been little government policy on caring for people with dementia' (p.490). She pointed out that 'the absence of a powerful political lobby or forum' contributed to the under development of policy for dementia and dementia care (ibid). The voice of Alzheimer's Scotland Action on Dementia has had limited influence on policy, although 'they regularly react to government initiatives' (ibid.).

In Korea, the under-development of dementia and dementia care stems from the under-development of social welfare. The Korean welfare system has been developed recently. In addition, the Korean welfare system is characterised as residual welfare. In this context, it

can easily be seen that social policies for older people with dementia are residual and selective. For example, free long-term care services and health services are provided only to sufferers in the low income bracket. What is more, the policy direction and intention of the Korean government are also an important cause of under-development. The government has based it on a national philosophy, 'family first, state later', and has shifted all the responsibility for dementia care onto the family. In this situation, there was no active organisation to represent families and people with dementia. Top-down policy making, which does not involve the representatives of dementia sufferers and families, results in the under-development of policies for older people with dementia.

Finally, there has been an increase of interest in long-term care policy, especially dementia care, in Scotland and Korea. In Scotland, the interests of dementia sufferers and their family carers were represented by psychologists during the 1980s (Inness, 2002). They influenced the development of various service provisions. Also, there have been institutional changes in Scotland. Sir Stewart Sutherland, who was the president of Alzheimer Scotland Action on Dementia, became the chair of the Royal Commission on Long-term Care. Following the Royal Commission, the Scottish government decided to implement free personal and nursing care (2002). Recently, the government announced 'Mental Health in Scotland Dementia: National Priority' (2008) after the Alzheimer Scotland reported on

‘the Dementia Epidemic’. It shows that social policy for dementia and dementia care is a recent development in Scotland.

On the other hand, the long-term care issues became serious in the late 1990s due to the advent of an ageing society in Korea. The recent development of social policy for older people with dementia has been influenced by the rapid growth of the ageing population, change of family structure and people’s attitudes towards care for older people in Korea. Korean people consider not only family but also state as providers caring for older people. As a result, Long-Term Care Insurance (hereafter LTCI) was enacted and implemented in 2007 and 2008 respectively. Furthermore, the Minister of Health, Welfare and Family Affairs announced the ‘General Plan for Dementia’ in 2008 to achieve early diagnoses of dementia. It asserts a free diagnosis of dementia not to include charges for MRI or CT scans, and vouchers for free dementia medicine for the low-income bracket (MHWF, 2008).

Meanwhile, it is natural that different countries have different cultural factors and social structures. First of all, while Scotland is a society based on Western Culture in which individualism is widespread (Giddens, 1998), Korea is an East Asian state in which Confucianism has developed (Goodmand, White & Kwon, 1998). Confucianism emphasises family obligation to care for their older relatives. Individualism stresses the ‘dignity of an individual, the

success and well-being of an individual, and the nuclear family' (Sung, 2000: 46).

Secondly, the introduction and development of social welfare is different between Scotland and Korea. Scottish welfare policy was introduced through a post war 'national consensus', whilst Korean welfare policy was introduced in order to achieve the legitimacy of an authoritarian military government.³ In the case of the development of social policy, Scotland has a longer history and broader coverage of social policy than Korea. Social policy has been developed in Scotland since the Victorian age, and the welfare state⁴ was established in 1945. It covers universal provisions, as can be seen in the introduction of National Insurance and the NHS. However, social

³ The welfare policies were established under 'development first, distribution later'. After independence from Japanese colonisation and the Korean War, poverty was also the most serious problem. Therefore, there were relief and institutional care based on the public assistance law. In the case of social insurance, the government established several insurances: the Government Employees Pension (GEP) in 1960, the Military Servicemen's Pension (MSP) in 1963, Industrial Accident Compensation Insurance (IACI) in 1963 and Private School Teachers' Pension (PSTP) in 1975. In addition, the Korean government introduced a health insurance law for citizens in 1976 and for government employees and private school teachers in 1979. In the same year, the government created a medical assistance programme for under the poverty line. These social insurance programmes began with large workplaces, and as a result, the coverage of these programmes was a very small proportion of Korean employees (Choi, 2002). In 1981, the Elderly Welfare Law was enacted, but the act was a declaration without compulsion. During this period, social policy was a carrot for the people to obey the military government and still marginal in order to achieve economic growth. There was not yet serious recognition of aging.

⁴ The 'Welfare state' has been created in Britain. Beveridge's report insists on the 'five giant evils': disease, idles, ignorance, squalor and want. He believes that the 'five giant evils' are combated through state action, for example, the National Health Service, full employment, state education, public housing, National Insurance and National Assistance. Attlee's Labour Government put this idea into practice. NI, NHS (Scotland), and National Assistance (hereafter NA) were introduced in 1946, 1947 and 1948 respectively. NI and NA are income security systems for older people whilst the NHS provides the health services for them. Despite NA providing social services for older people, the social services had not been developed as significantly and comprehensively as the income security and health care from 1945 to 1950.

policy in Korea has been provided since the 1960s with very small coverage. Unlike Scotland, the Korean government decided on a limited coverage of benefits. For example, the government at first provided for professional or white collar workers, but not manual workers. The national pension, work injury insurance and employment insurance based on universal coverage are the latest, from 1998 to 2000.⁵ Thus, older people have not been entitled to the national pension or other social insurance.

Thirdly, Scotland provides relatively institutional welfare, whereas Korea is based on comparatively residual welfare. Scotland provides free personal and nursing care for those aged 65 and over who need it. This costs from 145 pounds to 210 pounds a week depending on the result of assessment (Scottish Executive, 2006). Despite the criticism that free personal care is not as generous as its name suggests, and problems with its implementation, it is very generous compared to Korea which provides only free care services for those people under a strictly defined poverty line. Furthermore, Korea has stricter means tests than those of Scotland. Social assistance provides income support or services for older people in poverty with no children, or children who do not have the capability to care for their parents economically or physically. Therefore, older people in

⁵ Since 1997, the social security has been developed rapidly due to the Economic Crisis. To dealing with the economic crisis, all social insurance expands coverage. In detail, the National Pension covers all people regardless of employment category and Employment Insurance and Industrial Injury Insurance, finally, are comprehensive of employees in all the workplaces.

Korea are poor and less affected by state benefit or services than those in Scotland.

Some commentators assert that a comparative study between East and West is very difficult because of cultural and institutional differences. However, the above similar and different aspects give a rational reason for conducting a comparative study between the two countries. The similarities give an opportunity to compare the two countries in detail. It is interesting and valuable to see the different outcomes, although Scotland and Korea have similar social risks and social political bases. The different points give understanding of how different cultures and social systems, even though they have the same problems, care for those with dementia. This study will give social political suggestions according to the lessons learned from each country.

1.3 Overview of Thesis

This thesis is organised into 8 chapters. Chapter 1 introduces the motivations and purpose of this study, the significance of dementia and the rationale for a comparative social policy study between Scotland and Korea.

Chapter 2 includes a literature review, research questions, theory and analytical framework and methodology. It reviews previous studies focusing on dementia, dementia care, attitudes towards the diagnosis of dementia and the long-term care services in Scotland and Korea. Furthermore, it shows the different approaches to previous attitudes in Scotland and Korea. Then, it gives research questions which are drawn from previous studies. In the theory and analytical framework, it defines the importance of carers' attitudes. Furthermore, it examines culture and institution as determinants of these attitudes, then provides the framework according to cultural and institutional determinants. In the case of the methodology part, it explains reasons for using a qualitative approach with in-depth interviews; how the pilot interviews were undertaken; how interviewees were selected; how the fieldwork proceeded in Scotland and Korea, and how the interview data was analysed. It also contains the ethical considerations.

On the basis of a theoretical framework, carers' attitudes in Scotland and Korea are presented in chapters 3, 4, 5 and 6. Chapter 3 illustrates carers' attitudes towards the diagnosis of dementia. It focuses on how carers recognise the symptoms, how they felt at the time, what their reactions were after the symptoms of dementia had been noticed, how and when the older person with dementia is diagnosed, and what carers think about the treatment in Scotland and Korea. It also examines the differences and similarities between

Scottish carers and Korean carers. Moreover, it analyses how cultural and institutional determinants affect the carers' attitudes.

Chapter 4 investigates the carers' attitudes towards family care. It pays particular attention to how culture works in family care in Scotland and Korea. In detail, it demonstrates who family carers are, their living arrangements, and family care, particularly practical care, financial care, cognition care, family networks (which means other family members' participation in care), carers' burdens and their motivations in Scotland and Korea.

Chapter 5 explores how carers and older people with dementia utilise community care at home. To achieve this, the accessibility of services information and process of services delivery are discussed. It also investigates what services are involved in the lives of carers and older people with dementia, and how the services affect their lives in reality. It finds the influence of social policy on the lives of carers and older people with dementia in Scotland and Korea. Moreover, it investigates whether culture affects the utilisation of community care services at home.

Chapter 6 focuses on the attitudes towards residential care for older people with dementia. It explores the differences in carers' attitudes towards residential care under different cultures and social welfare policy in Scotland and Korea, based on their reasons. It discusses the stigma around residential care, consciousness of social

welfare, concerns over others' opinions, confidence in services, accessibility of services and affordability of residential care.

The final chapter is dedicated to analysing the results of the last four chapters and discussing what the significant determinants of attitudes are, and then provides a discussion regarding the main findings. It provides the implications on the social policy and academic area. Finally, it presents a discussion of the study's limitations and provides several suggestions for further research.

Chapter 2. Theory and Methodology

2.1 Literature Review

Perspectives on Dementia

The etymology of dementia is the Latin “demens” which means “without mind”, in other words ‘a lack of competence to manage one’s affairs’ (McKeith & Fairbairn, 2001). It has frequently been used since the early eighteenth century. The present common definition of dementia is as below (from Innes, 2009):

‘The term ‘dementia’ is used to describe the symptoms that occur when the brain is affected by specific diseases and conditions, including Alzheimer’s disease, strokes and many other rarer conditions. Symptoms of dementia include loss of memory, confusion and problems with speech and understanding’ (Alzheimer’s Society, 2006).

The biomedical definition of dementia has been widely used since the early nineteenth century (Holstein, 1997; McKeith & Fairbairn, 2001; Innes, 2009). In the same vein the biomedical perspective for

understanding dementia has been the dominant perspective till recently. However, the perspectives within dementia studies have changed from the biomedical to a psychological and sociological perspective. Therefore, this section will introduce each perspective on dementia and then provide the main perspective of this study and the reasons for it.

There are three main perspectives in understanding dementia: the biomedical model, the psychological model and the sociological model. The first two perspectives focus on an individual understanding of the condition, whereas the last one draws on a social exploration.

In detail, the biomedical and psychological perspectives have focused on individual characteristics in examining the dementia issue. According to Bond, the definition of biomedical dementia means that a person with dementia is seen as suffering from the loss of “normality” (Bond, 2001). This perspective defines dementia ‘as a medical problem’ and authorises ‘the medical profession to find some form of treatment for it’ (Bond, 2001: 45). This perspective stresses the medicalisation of dementia, which has the following characteristics: expert control, social control, individualisation of behaviour, and depoliticisation of behaviour⁶ (Bond, 2001). From the

⁶ Expert control means that ‘diagnosis and treatment is controlled by medical profession’ while social control suggests that ‘medicine has the power to legitimise and confer a social status and incorporates procedures by which the status of ill or well are judged by the doctors. The individualisation of behaviour implies that dementia is an individual problem, and thus ‘focuses on the individual and the diagnosis and treatment of the illness, rather than seeing an individual’s illness in the

viewpoint of the biomedical model, special regard is not paid to the social context in which an individual with dementia and carers are located (Harding & Palfry, 1997; Bond, 2001; Downs, 2000; Innes, 2009). Cheston and Bender (2003) also mention that the biomedical model does not treat a person with dementia as a person, that it oversimplifies the role of carer, is uninterested in the experiences of the sufferer, 'suggests strongly that loss of control is a major feature of dementia', encourages, rather than provides scientific evidence for, therapeutic nihilism and holds that the only hope lies in 'drug advances' (p.76), etc. Moreover, the critical point of the biomedical model shows that side effects and overdoses of medication for older people with dementia. In this culture, faster relief and quicker treatment is important. Medication can offer a quick and practical way to 'calm people down and lift their mood or to keep a ward seemingly clean and orderly' (ibid, 276).

However, the side effects of these drugs are ignored. For example, anti-psychotic medication can cause organic brain damage if used on a long-term basis (ibid., p.279) and even increase mortality. In fact, care homes are 'initiated too freely' to use anti-psychotic medication and are not stopped as quickly as they could be (Department of Health (hereafter DH), 2009: 59). This phenomenon

context of the social system'. Regarding the depoliticisation of behaviour, the 'biomedical model ignores the meaning of the individual's behaviour in the context of the social system, thus, the perspectives of the person with dementia and carers are ignored' (Bond, 2001: 45-46).

can be explained with an extreme example of the dominant biomedical model in dementia care.

The psychological perspective was developed out of the biomedical model (Bond, 2001:47). Kitwood (1997) pointed out that the medical factor is one of many factors rather than a single factor in understanding and caring for those with dementia; he proposed a new way of perceiving dementia in terms of the psychological perspective, arguing that the ‘biggest improvements in quality of life have not come from medical breakthroughs, but from the recognition of personhood⁷ in those who have dementia and its many practical applications’ (Kitwood, 1997: 10). According to his perspective, persons with dementia should be respected as individuals like everyone else. Moreover, Kitwood’s perspective has significantly influenced the practice of dementia care since then. The psychological perspective on dementia brought to an end the monopoly of the biomedical perspective and enlarged the understanding of dementia at an individual level (Bond, 2001; Downs, 2000; Innes: 2009).

However, the psychological perspective also locates dementia in the individual context like the biomedical perspective. Davis (2004) and Innes (2009) argued that the approach could cause the ‘guilt and

⁷ ‘Traditional concepts of personhood embody a number of principles. Individuals require a consciousness of self, a capacity for abstract thinking, the ability to act with intention, to live life according to a set of moral principles and to be accountable for their actions, and the capacity to form and manage relationships with others’ (Bond, 2001: 47). Kitwood (1997) stated that a new definition of personhood should be influenced by feelings, emotion, and the ability to live in relationships, and ‘reflect that persons with dementia are highly competent in these areas’ (ibid.).

despair of carers who cannot achieve the ideal of maintaining personhood’.

The sociological model of dementia, which has been developed recently (Harding & Palfry, 1997; Bond, 2001; Downs, 2000), is drawn from the ‘social model of disability’ (Oliver, 1990). This model argues that ‘disability is caused not by the person’s impairment but by physical and social barriers or circumstances which restrict people’s opportunities fully to engage in society’ (Downs, 2000:370). In this regard, the sociological perspective defines dementia as a social problem rather than an individual problem because it faces social risks such as any disabling risks that accrue from the limitations of the social and care environment. Likewise, this model provides an understanding of dementia in a social context such as political, economical, social and cultural environments (Downs, 2000; Bond, 2001). Therefore, dementia can be considered a barometer for understanding and analysing a nation’s social policy in issues such as health, the care system and culture.

The main perspective in this study is the sociological model but I do not deny the value of the biomedical, which is also important in early diagnosis, delay and relief of symptoms and pain for older people with dementia and their carers. However, for this study it is most useful to adopt the sociological perspective. Dementia should be understood as a social problem in the social context. Although individual experience and personality in understanding and handling a

disease are important, a person's characteristics are not isolated but are influenced by the social structure and culture where the individuals are located (Innes, 2009: 160). Cantley (2001) pointed out that social phenomena - for example, an 'increasing number of dementia cases, social changes in families, the emergence of social pressure from carers, older people and the Alzheimer's Society, rising professional interest, changes to the prospect of solutions from cure to care, media influence and public awareness, increased attention in public policy and resources, etc. (p.309) - contribute to recognising dementia as a social problem. In this context, it can be argued that carers' attitudes are shaped by social institutions and cultural factors.

This study will be based on the sociological model, which views dementia as a social illness in a social context. The reason why it is useful to adopt the sociological perspective is that this is more competitive than other perspectives in a comparative social policy study, because the sociological perspective focuses on different institutions, politics and cultures, and there are, in fact, many comparative studies on this perspective, while the biomedical model and psychological model pay attention to individual personality and different differences. This study is a comparative study between carers' attitudes in two countries, Scotland and Korea. Thus, the sociological perspective must be adopted for this study in terms of strategic utility.

Informal Care of Older People

The word ‘carer’ appeared in the English language less than forty years ago and carers in 1950s did not recognize themselves as such (Bytheway and Johnson, 2008: 223). Carers have legal recognition according to the Carers (Recognition and Services) Act in 1995(ibid.). In the social care literature, ‘carer’ appeared during late 1970s and the term ‘informal carers’, who provided unpaid care for family, friends or neighbours, became distinguished from ‘formal carers’, who provided paid carer for a person (Stalker, 2003: 16).

Bytheway and Johnson (2008) argued the concept of ‘carer’ was a social construction because the term involved the relationships between ‘individual experience and various interest groups - policy makers, researchers and pressure groups (p. 223). The carers’ movement shows that the term was created in the political sphere. The Rev. Mary Webster established the National Council for Single Women and her Dependants in 1965 in order to campaign for single women carers’ rights. In 1975, an Invalid Care Allowance was introduced for the people who gave up work to care for their older relatives (ibid. 224). The married women campaign established the Association of Carers in 1981 (Stalker, 2003). Two associations had been merged to form the Carers National Association in 1986 (Stalker, 2003; Bytheway and Johnson, 2008). In the same year, the Invalid

Care Allowance was extended to married and cohabiting women. The movement seriously questioned women's role as natural, voluntary family carers (Bytheway and Johnson, 2008). In 1981, the White Paper Growing Older emphasised family care and community care. It interpreted this to mean 'care by women'. Many studies focused on carers in the 1980s and as a result the term 'carer' became recognised as a professional term (ibid. 226).

Accordingly, carers tended to be recognised as women till the end of 1980s. However, the General Household Survey (Green, 1988) estimated that 40 per cent of the 6 million carers in Great Britain were male. Researchers were surprised by the number of male carers and drew attention to them (Arber & Ginn, 1990; Fisher 1997). Research on carers was extended from females to males and from the majority to the minority. In the early 1990s, there was a greater interest in minority ethnic groups (Atkin and Rollings 1992; Walker & Ahmad, 1994; Chamba et al. 1999). These studies compared the minority ethnic carers' experiences with their white counterparts' experiences.

The carers' movement contributed to establishing a typology of carers. For example, Twigg's three models of carers were introduced in 1989. The three models of carers imply the changing of perspective of carers in the social care agency along with movement of carers. Twigg (1989) focuses on the relationship between social welfare agency and carers. There are three models; carers as resources, carers as co-workers, and carers as co-clients (ibid.).

Carers as resources means that informal carers treated background and positioned prior to formal carers. Therefore, social care agencies provide services based on residualism. This model focuses on the dependent without considering carers' welfare. They ignored the conflicts of interest between carers and dependents and feared the substitution of formal care for informal care (ibid. 58). Treating carers as co-workers implies that informal carers are partners in the care enterprise. The aim is to preserve the carer's morale and their well-being to continue caring (Twigg, 1989: 59). Carers as co-clients paid attention to the carer's well being and supported their rights. Carers' needs assessments are mentioned in the Carers (Recognition and Services) Act 1995. This model aims to relieve the burden and strain of carers.

There has been a growing interest in the burden of carers. Grad and Sainsbury (1968) said that the term 'burden' created 'the mental health field to describe the stress experienced by families with a member facing severe and enduring mental health problems' (Stalker, 2003: 18). Research on carers' burdens have examined various aspects, such as stress, family and health problems, quality of daily life, employment status, financial matters and emotional impact (ibid.).

In the 1980s, dementia studies focused on the experience of carers of people with dementia (Innes, 2009:104). There has been an increased interest in carers' burden (Levin et al., 1989; Donaldson et

al., 1997; Marriott et al. 2000). Carers of older people with dementia experience a high level of depression, distress and strain (Donaldson et al., 1997; Marriott et al., 2000). Mafullul (2002) pointed out that the carer of persons with dementia experienced a greater burden than the carer of persons without dementia. In the case of emotional distress, 56 percent carers of persons with dementia suffered compared with 26 per cent of other carers (ibid). However, there were 91 cases in this study, thus they were too few to generalise the findings.

The stress of dementia carers is related to gender, especially affecting females, and relates to carers' physical and mental state, economic and social aspect, and the availability of formal and informal care support (Donaldson et al., 1997; Mittelman et al. 1996; Burns, 2000; Marriott et al., 2000). Studies have investigated and suggested benefits of professional and services interventions for carers (Mittelman et al., 1996; Marriott et al., 2000; Burns, 2000). Intervention on the emotional level, education and respite care services could reduce the carers' burden (Burns, 2000). In other words, a lack of participation of services and professionals causes a high level of carers' burden. The distress of care, thus, is reduced by service and professional participation (Burns, 2000; Marriott et al., 2000). The limitation of Marriott et al. and other dementia carers' burden studies was the small number of cases, too small to generalise their findings (Donaldson et al., 1997; Marriott et al. 2000).

Furthermore, the burden of carers is a strong predictor of institutionalization (Banerjee et al., 2003; Black & Almeida, 2004) and abusive behaviour (Wijeratne, 1997; Cooper et al., 2010). In the case of institutionalization, there were distinctive attitudes between carers of persons with dementia and carers of those without. As written before, general Scottish attitudes show that community care was broadly suggested for vulnerable adults except people with dementia (Curtice & Petch, 2002).

According to Cooper et al. (2010), those carers with anxiety and depression are reported to show more abusive behaviour. Moreover, the carers' burden affects attitudes towards residential care. For example, a higher level of burden is related to strong willingness to utilize residential care (Lee, 2004). Therefore, this study investigates the burden of carers. Moreover, it explores facts associated with their burden, such as lack of service intervention, family network, attitudes towards residential care, etc.

Scotland

In many previous studies, the majority of people in the UK⁸ recognised dementia as an illness, while some of them thought dementia was a natural phenomenon of ageing (Pollitt, 1994; Alzheimer Scotland, 2006).

⁸ Literatures, which include the UK as well as Scotland, will be reviewed in this part. This is because Scotland is part of the UK and many literatures examine Scotland in the UK.

With regard to understanding and diagnosing dementia in Scotland, 83 per cent of respondents in the survey of Alzheimer Scotland saw dementia as a physical disease of the brain and 80 per cent identified Alzheimer's as the most common form of dementia. On the other hand, 33 per cent of respondents thought that dementia was a normal part of ageing. This study points out the high percentage of the Scottish public that understand dementia as an illness, although a part of them still regarded it as 'an old person's disease', and therefore there was nothing to be done. It shows that 'awareness of dementia amongst the Scottish public must increase if they are to fully understand the illness and the type of help and support available' (Alzheimer Scotland, 2006).

Public understanding of dementia as an illness could remove the negative attitudes towards it. Moreover, Vernooij-Dassen and colleagues (2005) found that the stigma associated with the condition caused delays in recognition and diagnosis across eight European countries (including the UK). Previous studies also showed that a lack of knowledge caused stigma and an unwillingness to seek help (Alzheimer Scotland, 2006; Vernooij-Dassen et al., 2005). Therefore, public information or education to remove stigma results in earlier diagnosis. In this context, Iliffe and others (2005) state that the positive action of Alzheimer Societies in the UK may have helped to reduce the sense of shame about examining for and contracting dementia. Early diagnosis is also efficient in reducing the Health and

Social Services budget and improves the quality of life of carers and older people with dementia (Alzheimer Scotland, 2007; DH, 2009; Banerjee & Wittenberg, 2009). For example, early diagnosis and treatment results in ‘a reduction of 6 per cent in care home bed days for people with dementia entering care homes’ (Banerjee & Wittenberg, 2009: 3). Therefore, previous studies insisted that an important thing was a government strategy or priority to tackle the stigma and late diagnosis.

Concerning long-term care services, around 60 per cent of people with dementia live in the community and 40 per cent live in care homes or hospitals (Alzheimer Scotland, 2007: 33), but a Scottish survey of community care in 2002 recommended residential care for older people with dementia. This survey suggested public education and better quality of community care services in order to achieve social inclusion of persons with dementia or mental illness (Curtice & Petch, 2002). In other words, it is expected that public education will improve the possibility of social inclusion. Furthermore, a positive relationship between education level and accepting attitudes towards the person with mental illness has been found (ibid.). Public education provides knowledge on dementia and mental illness, and would make the stigma of this disease disappear.

In addition, a pre-requisite of social inclusion is good community care and support. People are concerned about the risks that are caused by the symptoms of an older person with dementia, but

they also confirm that residential care could manage the risks of, for instance, fires at home (ibid). Community care makes people feel confident in accepting a person with dementia as their neighbour due to control and watching out for the risks. It shows how social policy is important in changing people's attitudes and improving social inclusion for older people with dementia.⁹

Korea

Some studies, including that by Kim and Jun (1996), demonstrate that the caregivers in Korea have a vague and wrong understanding of dementia. In other words, Korean family caregivers understand it as a normal ageing symptom and mental illness, and families with sufferers conceal the problems in the community. The dominant argument of these studies shows that Confucian culture influences the diagnosis of dementia as well as the caregivers' understanding (Chee & Lewkoff, 2001; Jones et al., 2006; Lee et al., 2010).

With regard to diagnosis and the condition of dementia, a case study (Kim, 2002) showed that the majority of older people are presented with a moderate degree of dementia at diagnosis. In other

⁹ As seen above, there are a significant number using residential care and social acceptance of it in Scotland. Yet, it is undeniable that negative attitudes towards residential care still exist (Levin, 1989; Alzheimer Scotland, 2007; DH, 2009). There are low quality services, a lack of staff, and 'shadow of poorhouse', and these result in the negative attitudes or evaluation of residential care. Many studies emphasise that home care services help to delay institutionalisation (Levin, 1989; Mckee et al., 1999; Alzheimer Scotland, 2007; DH, 2009). In this context, carers are willing to use care home services at home rather than residential care. However, they also tend to feel a lack of social services at home. In fact, only 37 per cent felt that the services available were sufficient for their needs. 30 per cent said that day care was unavailable and 50 per cent could not access home support (Alzheimer Scotland, 2007).

words, a sufferer tends to be examined at a later stage in the development of the condition. This means that Korean people do not diagnose dementia early. In addition, people believed that dementia was incurable so that further medical examination was not valuable. This indicates that Korean caregivers had a lack of understanding of dementia (KIASHA, 1998; Lee, 2003).

Why is dementia diagnosed only once the condition has developed and why is there such a misunderstanding of it? The important clue is in the economic status of the older people with dementia. People are reluctant to use National Health Insurance (hereafter NHI) for dementia diagnosis due to expensive co-payment at the use of health services. In this context, it may be right that Korean carers' attitudes are determined by social conditions or institutions rather than culture or personality. The work of Kim (2002) is in line with this argument, but he did not positively examine the role of culture in his study.

Regarding attitudes towards the utilisation of long-term care services, many studies argue that Korean caregivers view with less favour institutional long-term care services because of their Confucian culture, which is mainly represented as filial piety (Kim, 2002; Choi, et al., 2002; Johnes et al., 2006; Cha, 2004; Lee, 1995; Kim et al., 2002; Park et al., 2004), although there has been a change in cultural tendency in Korea. In this vein, Kim (2002) showed that institutional care for relatives with dementia was not preferred in Korea because of

filial obligation. Lee (1995) also discovered that Korean people were against the use of long-term care services because they felt guilty using it for their parents. In this context, the study by Kim et al. (2002) showed that even if Korean carers could receive the highest quality continuous and professional care in care homes, they would still have a sense of guilt. There is a cultural explanation that Korean caregivers, compared with caregivers in western countries, have had to bear an additional psychological burden regarding the use of residential care because of Confucianism (Park et al., 2004).

There are, however, other studies which pay attention to institutions and social policy as well as culture. The studies by Chee and Levkoff (2001) and by Kim and Kim (2001) indicated the phenomenon of reduced utilisation of formal services in line with a lack of long-term care services as well as a filial responsibility. This explanation was attributed to both culture and social policy. These studies introduced the cultural factor in explaining the low utilisation of services at present, but also noted a change in Korean culture and family structure due to modernisation and industrialization. They predicted that the change would lead to a demand for formal care services in the future. Cho (2003) also argued that family caregivers' attitudes towards residential care for older people with dementia were relatively negative because of their guilt based on filial piety, the lack of residential care and residential care information. As can be seen above, these studies have added another factor, namely, social policy,

in addition to culture, but they do not state which one is more significant regarding low perceptions of residential care.

Although there are a range of factors underpinning the low use of care homes for dementia sufferers, overall the most dominant perspective in Korea is cultural, i.e. Confucianism (Kim, 2002; Choi, et al., 2002; Johnes et al., 2006; Cha, 2004; Lee, 1995; Kim et al., 2002; Park et al., 2004; Cho, 2003; KIASHA, 2005). To sum up, whereas previous studies in Scotland explain attitudes to diagnosis and long-term care services in terms of the social policy context, studies in Korea explain them by focusing on the cultural factor.

2.2 Research Questions

I began by wanting to ask why Scotland and Korea had different attitudes towards residential care. However, I changed my research question after pilot study. I expected that the attitudes between Scotland and Korea would be hugely different before the pilot study. For example, Scottish carers are more positive about using residential care or social services, while Korean carers have a negative attitude to use of residential care or social services.

However, the vague result of the pilot study seemed to be that Scottish carers' and Korea carers' attitudes were similar. Scottish

carers seemed more negative towards utilising residential care, while Korean carers were more positive to using residential care than I had expected. I realised that Korean carers' attitudes had changed.

Therefore, I wanted to focus solely on the change of Korean carers' attitudes. However, there was a lack of data about Korean carers' attitudes in the past. I therefore returned to the interview scripts and read them over minutely several times. I found that different attitudes existed to diagnosis, family care, community care and residential care, although there were also similarities between carers' attitudes in Scotland and Korea. I decided to return to the original question and started to review the literature, especially on attitudes towards diagnosis, family care, community care and residential care, in order to formulate further questions in this study.

Regarding dementia diagnosis, older people in Scotland tend to get diagnosed earlier than those in Korea. Asian carers believe that symptoms of dementia are normal in older people while Western carers think they are abnormal (Corner & Bond, 2004; Lee et al., 2010). Moreover, Asian carers felt a stigma regarding dementia because they recognised it as a mental disease (Mahoney et al., 2005; Corner & Bond, 2004). Lee and others (2010) supported this argument through the case of Korean American immigrants who perceive a strong stigma attached to Alzheimer's disease. This recognition of dementia influences diagnosis. In other words, Asian carers do not tend to be active in diagnosing dementia compared with Western

people. In this context, previous studies have explained that diagnosis delay among Asian carers is associated with the cultural norm (Lee et al., 2010).

With regard to carers' attitudes towards social services at home, it was asserted in previous studies that the attitudes are also different in Scotland and Korea. Many studies show that Asian carers are less in favour of using social services at home compared with Western carers, for cultural reasons (Young et al., 2002). In other words, Asian carers are reluctant to use care services at home because they do not want to receive guests in their house to care for their parents or relatives. This phenomenon has been explained in terms of the traditional cultural norm (Kim, 2004).

Previous studies also show that there are differences in attitudes towards residential care. In Scotland, around 70 per cent of respondents from the general public (Curtice & Petch, 2002) preferred residential care for an older person with dementia. On the other hand, in Korea, just 25 per cent of family caregivers of the older people who need long term care prefer to use residential care when sufferers' conditions worsened (Oh, 2002). This low preference for utilisation of the residential care in Korea has been explained according to Confucianism, which is characterised as filial piety (Jeung, 2002; Lee, 2002; Kim, 2001; Oh, 2002; Song, 2003; Cha, 2004; Kim & Kim, 2004). Oh (2002) argues that the Korean family still thinks in a traditional way and wants to care for older relatives, according to the

results of her study. Koreans believe that their parents will be treated badly if they send them into residential care (Jeung, 2002; Lee, 2002).

As can be seen from the above studies, the cultural factor is a main determinant of attitudes towards dementia diagnosis, social services at home and residential care in Asian societies, including Korea. This thesis starts with the question: Does the culture really explain the phenomenon of Asian people's attitudes towards dementia? This thesis could not help but wonder about the previous argument for the following reasons.

Filial duty, a core factor of Confucianism, is found in other cultures besides Asian cultures. In other words, the motivations for giving care to older people are similar in Western and Asian people. According to Sung (1994), the motivations for caregiving include love, responsibility, and repayment, which are common to both Koreans and Americans. Scottish family caregivers also seem to have a guilty feeling towards the older people with dementia who are put in long-term care services. A daughter has this dilemma:

‘I am ridden with guilt by decisions, whether I should or not refuse to have mum home or have mum in sheltered accommodation’ (Carers, 2004).

Because of this, people decide to care for their parents at home on their own, even though there is the choice of residential care.

In fact, the tradition of filial piety has been changing and even now seems to be very weak in modern Korean society. Korea today is

modernised and westernised, and as a result many older people live separately from their adult children, preferring nuclear families. According to a survey, 83.4 per cent of families are nuclear families, and around 60 per cent of older people live with their spouse or alone (Jeung et al., 2005). The tendency of the young generation is towards more individualistic lifestyles (Sung, 1995). Therefore, the cultural approach is not adequate to explain the different attitudes towards residential care.

In addition, the diagnosis of dementia is closely associated with wrong or insufficient knowledge of the illness, difficulty in accessing the health system, and low ability of social policy in a society rather, than a cultural dimension. Therefore, the stigma phenomenon should be explained in relevant institutions and knowledge.

If not culture, what can explain attitudes towards dementia? The research question in this thesis lies here. In other words, previous studies have asserted that the cultural influence from Confucianism is the most significant factor in understanding and explaining this phenomenon in Korea. In contrast, this thesis tries to focus not on Confucianism, but the impact of institutions on carers' attitudes towards dementia. Finally, this thesis will explore this argument with the following research question: What are the origins of different carers' attitudes in Scotland and in Korea? To answer the question, the questions below should be answered sequentially:

- What are the carers' attitudes towards the diagnosis, family care, social services at home and residential care of dementia sufferers in Scotland and Korea?
- How do the carers' attitudes differ between Scotland and Korea?
- How do cultural determinants or social policy affect the carers' attitudes?
- What is the most significant determinant of carers' attitudes?

2.3 Theory and Analytical Framework

Attitudes and Carers

The term "attitude" originally means a 'person's bodily posture', but it expands its meaning in social science into 'posture of the mind' (Oskamp, 1977:7). There are a variety of definitions: 'attitude as a mental set or disposition, attitude as a readiness to respond, the physiological basis of attitudes, their permanence, their learned nature, and their evaluative character' (ibid.). The most contemporary definition of attitude is 'a summary evaluation of an object of thought'

(Bohner & Wanke, 2002:5). In this context, Eagly and Chaiken define attitude as 'a psychological tendency that is expressed by evaluating a particular entity with some degree of favour or disfavour' (Eagly & Chaiken, 1998:269). In this thesis, the object is health and long-term care services, and carers taking care of older people with dementia and their attitude to health and long-term care services.

Why does this study focus on the carers rather than the older people with dementia? This is because the request and decision to use long-term care services is mainly not down to older people with dementia but their carers. Due to the characteristics of the disease, the carers make a decision on how to care for older people with dementia regarding the utilisation of services (Collins et al., 1991).

Why should carers' attitudes then be noted in social policy? This is because carers' attitudes affect the utilisation of health and long-term care services and this may help the budget and supply a plan for services and guides in the direction of social policy, etc. In addition, carers' attitudes are important not only in the lives of carers but also of older people with dementia. Carers' attitudes towards caring for older people and their use of long-term care affect the quality of the lives of older people and carers. For example, many researchers have proved that the use of home care services or respite care relieved carers' burdens and maintained that type of caring.

A study of carers' attitudes can unearth situations and the conditions underpinning social policies and institutions. It can explain the level and characteristics of any country's welfare.

Determinants of attitude: Culture and Institution

The purpose of this thesis is to explore the carers' attitudes towards health and long-term care services in Scotland and Korea. It is assumed that those attitudes are affected by a variety of determinants, such as social demographical character, economic factors, needs, social institutions and cultural norms, etc. However, this thesis focuses mainly on the two determinants of cultural and institutional attitudes. The reasons are as follows.

Firstly, sociological theories of attitudes are divided into the cultural and the institutional approach (Koelble, 1995; Hall & Taylor, 1996). Institutional theories believe that attitudes are shaped by institutions (March & Olsen, 1984; Thelen & Steinmo, 1992; Hall & Taylor, 1996), while cultural norm theories pay attention to social learning, social acceptance, and differential associations as the determinants of attitude (Seeman, 1981; Kiecolt, 1988).

Secondly, it is generally acknowledged that individual characteristics, such as demographical factors, economic factors and need factors, are influenced by institutional or cultural factors. Andersen and Newman's model (1973) is well known in attitude

studies. It focuses on long-term care, and argues that individual behaviour is related not only to individual characteristics but also to societal impact. Moreover, Moore (1969) also insisted that behavioural scientists attempt to explain behaviour according to interactions between the social structure and personal characteristics.

Thirdly, many attitude studies are approached from a cultural or institutional aspect. In the case of attitude studies in East Asia, the higher preference for caring for older people with dementia at home and the low-preference for using long-term care services are explained by Confucianism (cultural factor) (Ikels, 2002; Yeo et al., 1996). In the case of studies among Western countries, the preference for using health services is explained by resources and the accessibility of health systems (Andersen & Newman, 1973).

Fourthly, cultures and institutions have accumulated a broad framework on comparative studies. Esping-Andersen's (1990) welfare state regime theory has inspired a number of comparative attitude studies (Gundelach, 1994; Papadakis & Bean, 1993; Svallfors, 1997; Blekesaune & Quadagno, 2003: 417). These studies show the relationship between social policy characteristics and attitudes. Different countries have different cultures, therefore there are many comparative studies focusing on cultural differences (Jones et al., 2006; Navaie-Waliser et al., 2001; Milne & Chryssanthopoulou, 2005).

Institutional or cultural factors have been advanced and conceptualised based on many previous studies, therefore they are

variables as institutional or cultural factors. Accordingly, this thesis analyses carers' attitudes towards health and long-term care services in Scotland and Korea from the perspective of cultures and institutions.

Analytical Framework

Culture: Individualism vs. Confucianism

Culture shapes perceptions and behaviour towards older people with dementia (Cox, 1999). In this argument, some previous comparative studies show that differences between West and East in culture have led to different ways of thinking (Liu & Kending, 2000; Bengtson et al., 2000). In other words, Western society is based on a culture of individualism, whilst East Asian society is affected by Confucianism.

Western values of individualism are characterised by 'independence, self-reliance, autonomy, self-fulfilment, personal achievement, loose kinship ties, voluntary and egalitarian family relations, and less emphasis on duty to family members, greater emphasis on self-sufficiency' (Pyke & Bengtson, 1996:382) and a 'strong emphasis on the nuclear family' (Sung, 2000: 46). East Asian values of Confucianism emphasise filial piety which is characterised as 'cohesive ties between family members, family responsibility, interdependence between family members, family harmony and the individual as a unit of the family, and the pooling of individual members' resources to promote the well-being of parents and the

family' (ibid. p.45). Filial piety in Korea is 'the most important value that regulates young generations' attitudes and behaviour toward parents and elders, and influences policies for the treatment of the elderly' (Sung, 1998: 382).

These different cultural values and beliefs affect how they care for their parents and relatives. Social facilities tend to be responsible for them in individualism, whereas families may mainly be considered 'caring' for them in Confucianism (Pollitt, 1994; Downs, 2000:372). In other words, people in a Confucian culture would have strong family care while people in an individual culture would have weak family care. In this context, Korean people in a Confucian culture have less willingness to use long-term carer services, whereas Scottish people in an individualistic society prefer care homes for caring.

Institution: Institutional vs. Residual social welfare

Historical institutionalists concede that individuals may attempt to calculate their utility but that outcomes are shaped by a number of structural and institutional factors beyond an individual calculation or control (Koelble, 1995:242). Likewise, institutions matter because they shape, even determine, human behaviour (ibid. 232).

The welfare state is a kind of institution which equips social policy and welfare systems. In this vein, the institutional characteristics of the welfare state are assumed to influence attitudes

and opinions at the level of the individual citizen (Blekesaune & Quadagno, 2003: 417). Moreover, social welfare is significantly important in the health and long-term services area and there are many studies which show the relationship between attitudes and the social welfare system (Gundelach, 1994; Svallfors, 1997; Papadakis & Bean, 1993; Blekesaune & Quadagno, 2003: 417).

According to Wilensky and Lebeaux, social policy is divided into “institutional” and “residual” models, which are widely accepted in social welfare studies. Institutional social welfare views “the welfare services as normal” while residual social welfare regards them as abnormal or a last resort (Wilensky & Lebeaux, 1965). The latter implies that ‘the social welfare institutions should come into play only when the normal structures of supply, the family and the market, break down’ and the former means that welfare institutions should be ‘first line’ functions of modern industrial society’ (Wilensky & Lebeaux, 1965:138). These different social welfare models represent different values such as ‘economic individualism and free enterprise on the one hand, and security, equality, and humanitarianism on the other’ (ibid. 138). Moreover, institutional welfare supports the idea that poverty is caused by structural problems in society rather than individual fault. These social welfare systems may affect differently the recipients’ attitudes. In other words, a recipient recognises benefit and social services as right, ‘no stigma, no emergency, and no “abnormalcy”’ under institutional welfare, while a recipient believes

social welfare to be a charity, carrying stigma, temporary, and abnormal under residual social welfare (Wilensky & Lebeaux, 1965:139-40).

Accordingly, Korean people under the residual welfare system tend to be reluctant to use long-term care services or social welfare services because the services are not enough and are provided through a strict means test. On the other hand, Scottish people under a relatively institutional welfare system prefer to use the services because they are well equipped and are a part of their social right.

Culture, social welfare and attitudes

As seen above, understanding and treating dementia may depend on culture and institutions. There are, therefore, different attitudes towards understanding, diagnosis and treatment of dementia in East Asian and among Western family carers. Asian carers think of dementia as a normal part of the ageing process while Western carers recognise dementia as an illness (Downs, 2000). Moreover, East Asian carers are reluctant to have a diagnosis and treatment because of the stigma attached to dementia, which is recognised as a mental disease (Phillips, 1993; Hinton et al., 2000). Thus, cultural beliefs about dementia can result in avoidance of services and stigma (Innes, 2009).

On the other hand, social welfare may affect attitudes. For example, the high cost of the health service in Korea prohibits access to services while the free health service in Scotland presents no barrier

in terms of affordability for older people with dementia and carers. Moreover, active joint health policy with Alzheimer Scotland and the NHS's so-called 'National Priority of Dementia' has helped to reduce the stigma of having a family member diagnosed with dementia. In this context, this thesis will investigate the differences and similarities in the discovery of dementia symptoms, diagnosis and treatment in Scotland and Korea according to the cultural and social policy aspects (see Chapter 3).

In the case of family caring for older people with dementia, culture may be a dominant factor. There are five main aspects of family care: living arrangements, family network, family income support, carers' burden and motivation.

In detail, family income support, living arrangement and family network can show a distinction between cultures. Cultural preference theory often regards attitudes that favour 'living with and being supported by adult children' as ideal for elderly care in Asian societies. In contrast, the Western society tends to support the ideal of 'independent living and reluctance to be a burden on one's children' (Hu & Chou, 2000: 227). Thus, income support and living together and strong family network are strong in Asia compared with the West. As for family income in Korea, more than 84 per cent of older people depend on their offspring for economic support (Cho et al., 2004) and this is explained by filial piety. Why is the provision of adult children important to older family members? This is because the social safety

net is weak in Korea. The National Pension Programme, which was introduced in 1988, has not fully matured, and a full old-aged pension was first provided in 2008. Therefore, older people with dementia must depend on family income.

On the other hand, average Korean carers have respect and make sacrifices as the harmony of their family is the motivation for looking after their parents, while for the average American carers love and affection are the most significant motivations in caring for their parents (Lee & Sung, 1997; Sung, 2000). In this regard, the Koreans seem to score higher than the Americans on filial responsibility (Lee & Sung, 1997). However, Pung (2007) argued that people often dismiss filial piety as 'just an Asian cultural practice'. If you look through Western history, it is not confined to Asian cultures at all. Western history and literature offer examples of elderly parents living with their children over the centuries (Pung, 2007). In this context, we cannot state with any certainty that motivation will be much different between Scotland and Korea or that the cultural differences will make the modes of caring different.

Regarding a carer's mental and physical burden or distress, Kim (2001) and Youn et al. (1999) argued that Korean carers experienced higher levels of depression and anxiety than Western carers. Kim's study showed that Korean daughters in law and daughter caregivers had relatively poor physical health and higher levels of depression compared to their Western counterparts. Youn

and his colleagues (1990) pointed out that Korean caregivers reported poorer emotional health than Caucasian American and Korean American caregivers. Those studies concluded that higher degree of familialism causes distress for the caregiving, yet, this thesis will assert that the difference comes not from culture but institutions.

With regard to long-term care services, the attitudes about the use of the services are demonstrated by where the will originates. It can have its origin in both factors: culture and social welfare. In detail, the willingness to utilise services is associated with stigma, welfare consciousness, concern for others' opinions, confidence in service quality, access to services and affordability.

In the case of stigma, a strong filial piety culture among Korean caregivers makes them less likely to use residential care because they feel the shame of “putting away” their relatives in a home. Equally, the attitude towards care services at home may be less negative. However, the stigma is always from a cultural aspect, filial duty, because it is closely related to the poverty of the social welfare system. Under a residual welfare system, family carers are likely to view residential care as poor houses, and therefore feel shame in resorting to them.

In the case of consciousness of social welfare, people in a Confucian culture with residual social welfare tend to feel social welfare is a charity. On the other hand, under an institutional social welfare system, older people who believe that social services are a

right have a higher utilisation of formal services (Logan & Spitz, 1994). Moreover, they may have more willingness to use services at home and residential care (Choi, 2005).

Regarding others' social expectation or criticism, people under Confucianism may have more of a sense of guilt than those under individualism when it comes to leaving their relatives and parents in care homes. Likewise, ethnic and cultural variations may also influence family perceptions about the acceptability of seeking help outside the family.

In relation to the use of long-term care services, carers may be reluctant to use them because they feel a sense of guilt based on Confucianism when their relatives are committed to others to handle. Also, families may be concerned that acceptance of home help means relinquishing family control to strangers (Gwyther, 1989) or that their relative will be cared for improperly by in-home workers (Gwyther, 1990). Yet, there may be another reason why they dislike it. This stems from the low quality of the services. In such cases, caregivers of relatives with dementia may have particular concerns related to the ability of service providers to understand and accommodate the needs of dementia patients (Collins et al., 1991:757).

In the case of access, where an older person with dementia gains entry to the health and social care system and continues to receive care, this is closely related to institutions. The degree of access in any system varies according to such things as direct out-of-pocket

costs for health and long-term care to the older person (Andersen et al., 1970). Universal free services are more accessible to older people with dementia (ibid.). There are free personal and nursing care services available in Scotland, while Korean older people have had to pay co-payment to use long-term care services since 2008.

In Scotland, there are community care services, such as day centres, respite care services, home help services, laundry services, meals services, and holidays (NHS Health Scotland, 2003). Some services are free, depending on the capability for daily living of those who are aged 65 or over. Some services are dependent on a financial assessment. Those services share the burden of family caregivers. In Korea, there are also community care services, although with a very limited number of places. Additionally, the services are not free, except for the poor who receive income support, and home help services are very expensive if you engage them privately. Therefore, the emotional and physical distress or burden of care for families with older people with dementia at home in Scotland is much less than in Korea due to the accessibility of community care services.

Affordability can be examined in terms of institutions because it is one of the significant factors in the use of long-term care services. According to Kim (2004), financial considerations had the most effect upon the preference for utilising formal services.

For example, Korean older people are generally poor because of the late establishment of the pension system (Cho et al., 2004).

Moreover, the present care services in Korea are accessed mainly by two minorities: the very poor and the rich (Oh & Warnes, 2001). As mentioned above, the poor who are in NBLS can receive care services without charge. However, private nursing homes or residential homes are very expensive for the middle class. The care cost for one older person with dementia is estimated to be about £3,573.5(₩7,147,000) ~ £4,576.5(₩9,153,000) per year in Korea (National Health Insurance Co-operation, 2005). Furthermore, private care homes are annually £16,930 with a deposit of £5,643. The minimum wage and average wage for labour in a city in Korea is £4,859 and £23,903 per year, in 2006 respectively (Korea National Statistical Office, 2007). However, the burden of using care homes will decrease due to the introduction of LTCI in Korea. A person will still pay 20 per cent of their fee. Although there will be a reduction in care homes or care service fees, they will still represent extra expenditure, and the cost of caring for older people with dementia will still be a burden on the family in Korea. Therefore, this will be a barrier to the use of care homes in Korea.

In Scotland, the state covered personal care up to £145 per a week and nursing care up to £65 per week in 2006 (The Scottish Government, 2006). Consequently, if someone needs free personal and nursing care, they may receive care at a maximum of £210 per week. However, older people still need to pay for their accommodation costs. The average weekly charge in care homes for

older people in 2006 was £467 and £557 in Scotland and the city of Edinburgh respectively. Thus, they should charge an average accommodation cost of £257 per week or £347 per week. Although the charge in care homes is expensive for the middle or better paid working classes, older people usually receive their pension in Scotland and the financial assessment does not take into account their adult children's means, unlike their Korean counterpart. Therefore, it is a much more generous welfare system than in Korea.

2.4 Methodology

Rationale for Qualitative Research

Ontology is a theory of 'being'. According to Snape and Spencer (2003), 'ontology is concerned with the nature of social world and what can be known about it' (p.22). Ontology is the starting question of a piece of research (Grix, 2002: 177). A researcher's ontological position is the researchers' belief or view about the nature of the social world. There are many theories to help understand 'reality'.

This study is interested in human attitudes in different countries. The existing attitudes are affected by institutions (social policy) and culture (Koelble, 1995; Hall & Taylor, 1996). In fact,

human beings' attitudes exist, not in a vacuum, but in a society which is structured through institutions and culture. This study believes that the different attitudes in Korea and Scotland exist because of institutions and social policy rather than culture.

The ontological position of this study is 'institutionalism', which is concerned with how attitudes are affected by institutions (March & Olsen, 1984, Thelen & Steinmo, 1992; Hall & Taylor, 1996). A institution leads to the preferences, goals and visions of human beings as well as activities according to previous studies (Koelble, 1995; Pierson, 1996). In other words, there is a significant symbiosis between attitudes and institutions.

What is more basic is that institutions reflect the ontological conditions of human relationships, especially political relationships. One new form of institutionalisms, historical institutionalism, pays attention to the relations between politics and institutions. An institution creates a political relation as the latter makes the former (Thelen and Steinmo, 1992; Pontusson, 1995). Most institutionalists said as follows: "institutions shape politics"(Koelble, 1995: 238) and "politics produce policies" (Pierson, 1994: 39). This thesis is based on institutionalism in the ontological perspective.

This study focuses on the origin of different attitudes of family carers in Scotland and Korea. Previous studies emphasize a cultural aspect to explain the nature of different attitudes between the West and East-Asia (Lui & Kending, 2000; Bengtson et al., 2000).

However, this study insists that institutions shaping social policy are more significant than culture. Social policy, thus, is more significant than culture in understanding the different attitudes in Scotland and Korea. In short, the origin of different attitudes is in an institution. This study does not deny the influence of culture but it holds that culture is not the single most important fact to explain different attitudes between the West and East-Asia.

On the other hand, epistemology is a theory of knowledge. It is concerned with 'the nature of knowledge and how it can be acquired' (Snape & Spencer, 2003: 23). There are two important aspects of epistemology, positivism¹⁰ and interpretivism (ibid.).

In order to explore the belief of this study, the epistemological position is interpretivism, which holds that 'natural science methods (positivism method) are not appropriate for social investigation because the social world is not governed by regularities that hold law-like properties' (Snape & Spencer, 2003: 23). A researcher has to 'understand the social world through the participants' and their own perspectives' (ibid.). This study is based on interpretivism in order to understand the reality of carers attitudes and what caring means to carers.

This thesis started from my experience of voluntary work. I observed and interpreted the phenomenon of family carers in Scotland

¹⁰ Positivism claims that 'methods of the natural sciences are appropriate for social enquiry because human behaviour is governed by law-like regularities; and that it is possible to carry out independent, objective and value free social research' (Snape & Spencer, 2003: 23).

and Korea. According to the experience, I believed that the different attitudes among family carers in Scotland and Korea had been produced from the social policy (social institutions) rather than culture. The belief of my thesis was established through conversation and interaction with family carers in Scotland and Korea. In order to explore the belief of this study, I have used the qualitative approach to find the reality of family carers' attitudes. Communication through interview provides rich data and the reality of family care, thus the interview method was employed in this research.

According to Glaser and Strauss (1967), grounded theory is a method for drawing "the discovery of theory from data" (p.1). It means that a theory stems from a phenomenon. It is claimed that "these decisions are not based on a preconceived theoretical framework" (ibid. 45). Thus, grounded theory argues that a piece of research should be based on observation, refusing to privilege any one theoretical perspective, categorising data and making the theory fit.

From this point of view, it is not proper that this thesis adopts the grounded theory for the following reasons: this study does not formulate a new theory. Rather, it is to prove a previous theory, new institutionalism. In other words, this thesis is based on a theoretical perspective according to which an institution is more significant in understanding different attitudes between Scotland and Korea. Likewise, this thesis is based on a theoretical analysis framework. It centres on family caring and family carers' attitudes in Scotland and

Korea. It assumes that culture is a less significant factor in family carers' attitudes than institutions. It has as its preconception a theoretical framework designed to focus on the beliefs of the researcher.

This study aims to discover and assess experiential information about caring for dementia through the actual words and statements of the caregivers. Moreover, this study focuses on exploring influential determinants of attitude. These characteristics of the subject and object of this thesis may necessitate a qualitative rather than quantitative method. This is because, as Bryman (1988) said, the qualitative method gives a deeper understanding of social policy systems and the reality of people's lives in different countries.

In this context, it is expected that a qualitative approach will offer a rich exploration of the different attitudes between carers in Scotland and Korea. According to Ritchie, one of the features of qualitative research is:

‘Explanatory research is concerned with why phenomena occur and the forces and influences that drive their occurrence. Because of its facility to examine subjects in depth, qualitative research provides a unique tool for studying what lies behind, or underpins, a decision, attitude, behaviour or other phenomena’ (Ritchie, 2003:28).

A qualitative methodology, likewise, provides deeper understanding of individual behaviour and attitudes (Silverman, 2000). For example, Kim and Youn (1994) said that, in a face to face interview, many Koreans respond by saying that the psychological effect of caregiving is severe, although in a questionnaire, they assert that the effect is mild.

Yet, Korea has been dominated by quantitative methods, as shown in the Literature Review. Previous studies have used the quantitative method to discover the facts about the utilisation of community care services among family caregivers in Korea. However, the quantitative method, in which ‘findings are arrived at by statistical procedures’ (Strauss & Corbin, 1998:11), cannot describe the reality of any caregiver’s experience and situation.

‘Qualitative research is the way in which people being studied understand and interpret their social reality and this is one of the central motifs of qualitative research’ (Bryman, 1988:8).

Accordingly, quantitative data faces difficulties in describing the conflicting circumstances of caregiving for older people with dementia. The statistics alone make it difficult to explain the reality of the problems of caregiving. As mentioned above, a qualitative method gives a more in-depth exploration of carers’ attitudes and the origin of

those attitudes. This study, therefore, is based on a qualitative approach.

Selecting interviewees

This study uses purposive sampling. This is when participants are selected according to their 'particular features or characteristics', which facilitate the exploration and understanding of the central purpose of the study (Ritchie et al., 2003:78). These features of participants may be socio-demographic characteristics or specific roles, behaviour, experiences, etc (ibid. 78).

The subjects of this study are the family carers of older people with dementia in Scotland and Korea. This study chose those caring for older people with dementia at home. As discussed before, caring at home usually involves almost all the problems facing caregivers, such as the burden of care giving, economic problems, conflict among family members, ethical or moral pressure. The respondents described their understanding of dementia, their motivation for caring at home, the needs of caregiving at home, whether they prefer to use residential care or care at a home, and if they want to use care homes, what their reasons are; or if they do not want to use care homes, why not.

The interviewees are present family carers in Scotland and Korea. This study did not try to include former carers of those now in nursing home because of their different situation and difficult access.

Firstly, former carers of those now in nursing homes may not show problems of long-term care services or negative social attitudes towards residential care because they already use the residential care. Secondly, present family carers are in dilemma which could lead to many conflict situations at present, thus making it difficult to compare with former carers. Thirdly, it is very difficult to arrange to meet former carers due to stigma or guilt over using residential care for their relative with dementia.

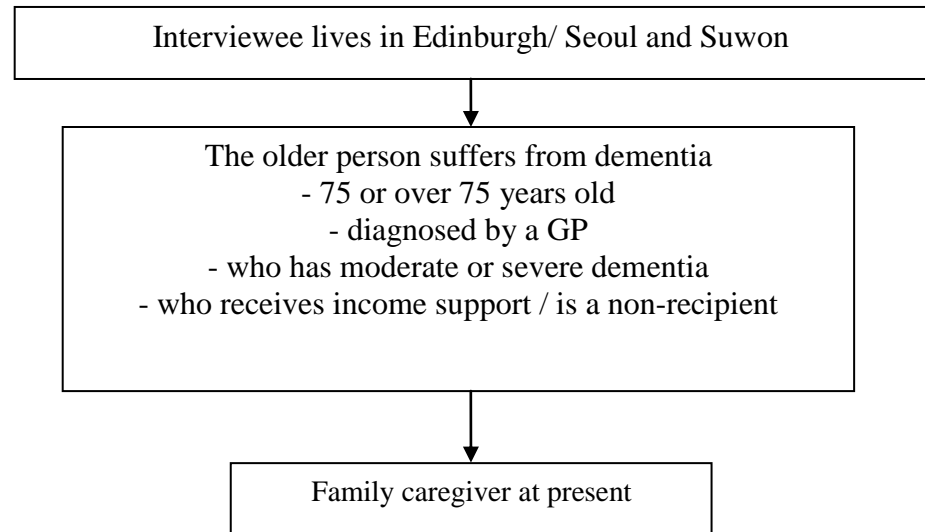
I chose to limit my sample to the carers of persons over 75 years old, diagnosed with moderate or severe dementia by a GP and living at home. Dementia develops slowly. If someone who is 65 years old has moderate or severe dementia, his or her dementia must have developed from a relatively younger age. It means that their family caregivers have a different experience. Therefore, it is not suitable to choose a subject aged 65 years old. Kenneth and Stadnyk suggested that dementia will occur in an estimated 2.2-8.4 per cent, 10.5-16.3 per cent, and 15.2-38.9 per cent of the population aged over 65, 75 and 85 respectively (quoted in Woo, 1997). The incidence of dementia increases rapidly in those who are in their 80s. However, if the age is limited to those in their 80s it might be difficult to find cases. Therefore, 75 years has been chosen for this study.

As mentioned above, the level of dementia should be moderate or severe. The family caregivers of older people with

moderate or severe dementia usually face more problems and are more likely to favour care homes than others (Levin et al., 1989).

For this research, economic status is divided into income support recipient or non-recipient. Economic circumstances affect preferences in using care home services. Those lower down the socio-economic scale are more likely to use care homes than others. Research carried out by the Personal Social Services Research Unit (PSSRU) suggests that admission rates are at their highest at the lower and upper ends of the Socio-Economic scale. Work undertaken by PSSRU for the Royal Commission on Long Term Care found that people over 70 who are in receipt of income support prior to admission, i.e. at the lower end of the social-economic scale, are more likely to enter institutional care than those who are not in receipt of income support (Almond et al., 1999, Market Survey, 2002). Therefore, this study assumes that someone who qualifies for income support is more likely to use care homes. According to the Royal Commission on Long Term Care, income support recipients are significantly more likely than others to enter a care home. Income support recipients, unlike non-recipients, can receive care home services without charge.

Figure 2- 1 Selecting interviewees



In the beginning, I had planned to interview 20 carers in each city. This number had to be revised because of problems of access, and in particular, access to interviewees in the lower income group was very difficult, both in Scotland and in Korea (Seoul). However, the findings from interviewees were repeated even though relatively small numbers of interviews were conducted. Therefore, this study carried out a total of 42 interviews: 14 in Edinburgh (Scotland), 14 in Seoul (Korea), and 14 in Suwon (Korea), as Table 2-1 shows. In Korea, some of the interviews were conducted in a different city because Suwon had been providing a pilot LTCI scheme which extended long-term care services from the poor older people to general older people with long-term illness or disability, whereas Seoul at the time was only providing care services for older people in poverty.

The contact with interviewees in three cities was established in two ways. The interviewees in Edinburgh and Seoul were accessed

through voluntary organisations while the interviewees in Suwon were found through long-term care pilot scheme team. I also sampled interviewees by age, symptom and property, and there were therefore no significant differences between interviewees from the pilot scheme team and from voluntary organisations.

Table 2- 1 Interviewed family caregivers

Nation	Scotland (14)	Korea (28)	
City	Edinburgh	Seoul	Suwon
Total	14	14	14
Income support	7	7	7
Non-income support	7	7	7

Table 2-2 provides a profile of my interviewees. The average age of carers was around 56 in Scotland, Seoul and Suwon. The average age of older people with dementia in this study was over 80, for example, 80 in Scotland, 82.9 in Seoul, 81.8 in Suwon. The number of female carers was higher than male carers in both Scotland and Korea. The gender composition rate was the same between Scotland (8 Females: 6 Males) and Seoul, but the majority (11) of carers in Suwon was female. In the case of older people with dementia, the majority were female, for example, 11 women in Scotland, 13 women in Seoul, 10 women in Suwon. The period since symptoms were first revealed was 7.1 years in Scotland, 6.1 years in Seoul, and 6 years in Suwon, at the point of interview in 2007. Those differences in age, gender and period of symptoms in different places may result in different attitudes,

although the differences are not great. Thus, the analysis endeavours to take this into account.

Table 2- 2 Profiles of interviewee and older people with dementia

		Carer	Relationship and Age	Older people with dementia	Date of Diagnosis(symptom)
S C O T L A N D	H I	Mrs. A	Daughter (50)	Mother (75, F)	2003 (2002)
		Mrs. B	Wife (71)	Husband (79, M)	2001 (2001)
		Miss. C	Daughter (46)	Mother (82, F)	2001 (2001)
		Mr. D	Son (58)	Father (85, M)	2003 (2003)
		Mr. E	Son (42)	Mother (77, F)	2003-04(03-04)
		Mrs. F	Wife (73)	Husband (75, M)	2000 (2000)
		Mr. G	Husband (73)	Wife (77, F)	2000 (2000)
	L I	Mr. H	Husband (83)	Wife (80, F)	1999 (1999)
		Mr. I	Husband (75)	Wife (78, F)	1996 (1996)
		Mr. J	Husband (78)	Wife (75, F)	2002 (2002)
		Mrs. K	Daughter (43)	Mother (79, F)	1993 (1993)
		Mrs. L	Daughter (45)	Mother (83, F)	2001 (2001)
		Mrs. M	Daughter (58)	Mother (93, F)	2002 (2002)
		Mrs. N	Daughter (59)	Mother (82, F)	1996 (1996)
S E O U L	H I	Mrs. A1	Daughter (52)	Mother (82, F)	2005 (02-03)
		Mr. B1	Husband (77)	Wife (75, F)	2001 (1998)
		Mr. C1	Son (59)	Mother (80, F)	2007 (2002)
		Mr. D1	Son (59)	Mother (86, F)	2007 (04-05)
		Mr. E1	Son (42)	Mother (78, F)	2006 (1999-2000)
		Mrs. F1	Daughter (68)	Mother (90, F)	1997 (1997)
		Mrs. G1	Daughter (63)	Father (91, M)	1997 (1997)
	L I	Mrs. H1	Daughter (49)	Mother (83, F)	2006 (2000)
		Miss. I1	Daughter (59)	Mother (80, F)	2004 (2002)
		Mr. J1	Husband (78)	Wife (75, F)	2007 (2004-05)
		Mrs. K1	Niece (53)	Aunt (90, F)	2006 (1997)
		Mrs. L1	Daughter-in-law (44)	Mother in law (83, F)	2006 (2004)
		Mr. M1	Grandson (29)	Grandmother (88, F)	2007 (2005)
		Miss. N1	Daughter (48)	Mother (80, F)	2004 (2001)
S U W O N	H I	Mrs. A2	Wife (80)	Husband (86, M)	2007 (2000-1999)
		Mrs. B2	Wife (72)	Husband (77, M)	2004 (1997)
		Mrs. C2	Daughter-in-law (48)	Father in law (89, M)	2007 (2006)
		Mr. D2	Son (67)	Mother (88, F)	2007 (2002)
		Mrs. E2	Daughter-in-law (55)	Mother in law (80, F)	2001 (2000)
		Mr. F2	Son (52)	Mother (82, F)	2003 (2003)
		Mrs. G2	Daughter-in-law (39)	Mother in law (78, F)	2006 (2003)
	L I	Mr. H2	Nephew (40)	Aunt (79, F)	2007 (2002)
		Mrs. I2	Daughter (52)	Mother (88, F)	2006 (2005)
		Mrs. J2	Daughter (42)	Mother (76, F)	2005 (1995)
		Mrs. K2	Wife (77)	Husband (85, M)	2005 (2005)
		Mrs. L2	Daughter (60)	Mother (82, F)	2004 (2001)
		Mrs. M2	Daughter (61)	Mother (78, F)	2004 (2004)
		Mrs. N2	Daughter (44)	Mother (77, F)	2007 (1997)

On the other hand, my samples have limitations, such as the small number of cases focusing on three cities. Therefore, it may be difficult to generalise from the study in relation to the family carers of older people with dementia. However, my study is an exploratory one, based on qualitative methods. These are very effective in achieving an in-depth understanding of a phenomenon and suitable for sampling for purposive studies. Further, the emergence of repetition of experiences in my samples suggests that the findings from the interviewees do not show exclusive or contradictory attitudes of majority family carers of older people with dementia at home. This supports the sample in this study as representative of the family carers of older people with dementia in general.

Data Collection

Central to my method is my realisation that the process of care has four key stages. I divided the process of care into four key stages - diagnosis and treatment of dementia, family care, community care and residential care. This process of care is based on social policy involvement and stage of care. These four areas are significant in understanding family caring and carers' attitudes. The diagnosis and treatment of dementia are the starting points of care and family care is the first care step of dementia. Family care of older people with dementia involves community care, for example day care centre,

personal care, nursing care and respite care, etc. Residential care implies family carers no longer providing proper care, or when the condition of dementia is getting worse. The four areas in this study provide the whole picture of family care and its dilemmas. Accordingly, these stages provided me with a framework for the interviews and for analysis.

Data collection was done in two ways: documents and qualitative interviews. Documents are a major feature of contemporary society and an important source of data (Murphy *et al.*, 1998). This study collected documents including media reports, government papers and publicity materials. It included news related to older people with dementia, attitude surveys in Scotland and Korea, and legislation for older people with dementia and carers, internet materials relating to carers' attitudes and older people with dementia, and publications from the relevant organisation for Alzheimer's or dementia.

Therefore, this study used individual interviews as a method for investigating carers' attitudes. Ritchie (2003) has pointed out the value of individual interviews:

'Individual interviews are probably the most widely used method in qualitative research ... [They provide] an opportunity for detailed investigation of people's perspectives for in-depth understanding of the personal

context within which the research phenomena are located, and for very detailed subject coverage' (Ritchie, 2003:36).

This study's challenge was to explore carers' attitudes, therefore it required an in-depth understanding of the phenomena according to the individuals' contexts. It investigates in detail their motivation for being carers, their attitudes towards the diagnosis of dementia, social services at home and residential care services. These 'generally require the detailed personal focus that in-depth interviews allow' (Lewis, 2003:58). Moreover, this in-depth understanding of attitudes provides the determinant of carers' attitudes, and consequently interviews are the best method for covering this topic.

This study uses a semi-structured interview which is characterised thus:

'The interviewer has worked out a set of questions in advance, but is free to modify their order based upon her perception of what seems most appropriate in the context of the 'conversation', can change the way they are worded, give explanations, leave out particular questions which seem inappropriate with a particular interviewee or include additional ones' (Robson, 1993:231).

Likewise, semi-structured interviews provide a rich in-depth understanding of carers and older people with dementia through conversations based on key questions.

Interview schedule and pilot project

Key questions for this interview have been drawn from previous studies and the experiences of older people with dementia. For example, the question of the motivation of caring refers to the Sung (1994) study and Collins et al. (1991). The question of evaluation and preference of long-term care services is based on the study by Collins et al. (1991). The questions focussing on barriers to the uptake of care services and opinions about government participation in care provision are based on Whittick (1985) and Collins et al. (1991). These questions include personal information on older people with dementia and carers, i.e. sex, age, income, relationship with carer, etc. There are key questions about the diagnosis of dementia, family care, social services in the community and residential care (see Appendix 1).

The questions had previously been used in the pilot studies in Scotland. A pilot study 'helps to throw up some of the inevitable problems of converting research design into reality' (Robson, 1993:301). Therefore, during the pilot stage in Scotland, the data was collected from individual caregivers in in-depth interviews.

The pilot study had been organised through day care programme co-originators. First of all, I contacted day care

programme co-ordinators and introduced the purpose of this research and the interview setting in order to ask about pilot interviews. I passed my letter to them and asked them to phone carers. They called the carers to ask about participating in the pilot interviews. Then I contacted interviewees to arrange their interviews.

The interviews took place at their homes and were held at a convenient time for the carers. They were one and a half hours in duration, including the introduction. The interviews included three stages: the introduction, the main interview, and the ending. Each interview opened with an introduction to the researcher, the purpose of the study, an introduction to the process of interview, and an agreement on recording and confidentiality. The main interview involved talking about experiences of caring, motivations for caring, caring situations, financial (government support) situations and attitudes toward residential care, and anything else the interviewee wanted to mention. At the end, I gave them a Korean book marked with words of gratitude for their participation in the interviews. I also asked for future contact if I had further questions or if they had any questions. After one interview, the interviewee wanted to get information on respite care places. I sent them some information from Alzheimer Scotland.

After the pilot interview, I reviewed my interview based on a checklist, i.e. practical interview time, how to manage the process of interview, whether interviewees understood the interview questions,

whether the interview questions achieved what I wanted to know, and interviewees' reaction towards interview questions, particularly economic questions. According to the assessment of the pilot interviews, some suggestions arose. The interview schedule needed to be shorter. An hour and a half interview was ok, but might be too long for the interviewee and interviewer as well. The interviewer needed to memorise the questions, show sympathy towards the responses and identify the significant questions. I did not use the term of filial piety but described the Korean family situation to make them understand before asking about motivation. Whenever I listened to stories of hardship, I showed my sympathy and was sorry to hear them. Regarding the economic questions, I needed to provide an information sheet on residential care subsidies, then ticked the box which suited their relative situation. I asked for personal information during the final stage, like their education and age.

After the pilot study, the semi-structured questions, which were based on theoretical framework, were slightly revised. There were four stages of dementia care, for example, diagnosis, family care, community care and residential care. The key questions regarding the diagnosis of dementia were: when they found the first symptoms of dementia, what was their recognition and reaction? And what is their belief regarding treatment? In the case of family care, the focus was on motivation, other family involvement, what care they provide, family income support and living arrangements. In the case of

community care, the interviews centred on how they got information, what they received, and how they regarded the services. This directed me to ask the questions on what they thought about residential care, their attitudes towards the utilisation of services, and what the reasons were behind their attitudes towards utilisation, etc (see Appendix 1).

Data Production in Scotland and Korea

The fieldwork in Scotland was conducted from March to August 2007. The fieldwork was divided into the pilot study and interviews.

I met key people, like programme organisers, nurses and a research and information officer in City of Edinburgh Council Department of Health and Social care, etc. The meeting with the research and information officer in the Council was very helpful in giving me ideas on managing my fieldwork. The interviews were organised through programme organisers who work in the voluntary sector. They introduced and organised more than 20 interviews. The interview process was more or less the same as the pilot study. Finally, the 14 cases of 20 interviewees were qualified for the conditions of interviewee in this study.

On the other hand, I tried to collect documentary data, such as literature, and often contacted supervisors by email and through meetings in order to discuss how to conduct or report the results of interviews.

I also tried to arrange fieldwork in Korea. Through Professor Kim, who has studied LTCI and was interested in my study as an ex-supervisor for my MSc dissertation, I was able to obtain 32 cases and several professionals for a broader understanding of the long-term care policy in Korea. From October to November 2007, 28 cases of interviews were selected for my thesis as data because others did not fit the condition of interviewee and some interviewees did not cover all the key questions.

Interviews in Korea took place in Suwon and Seoul. Interviews in Suwon ran from 2nd October to the 27th October. Suwon has been a LTCI pilot project area for three years. The pilot scheme had been developed for policy development concerning the aged society in Korea. The state social care system in 2007 covered only older people in poverty. The LTCI pilot scheme covered older people aged 65 or over with long-term illness. Moreover, the pilot scheme is a more generous system than the present one (2007) although older people have co-payment according to their means (see further discussion in Chapter 5). Professor Kim, who is one of the significant people in long-term care policy making, introduced me to the key people who are directors of the pilot scheme in Suwon. I met Mr. Jo, GH (the director of the National Health Insurance head office in Kyung-In), introduced my study, and asked for his help in my fieldwork. Thanks to his help, a care manager in the NHI Office in East Suwon gave me a list of interviewees on the 8th October. I arranged interviews.

Finding interviewees who were means-tested or in the NBLS System was difficult, so I also visited the NHI Office in West Suwon and they gave me a list of interviewees on the 18th October. Finally, the interviews could be finished in the pilot scheme on the 27th October.

Interviews in Seoul, where they had not introduced LTCI pilot scheme yet, were carried out from the 29th October to the 26th November 2007. Firstly, I met a director of the health network. She introduced some people in the field. There were a few interviewees who had agreed to participate in my interview. I tried to contact the dementia programme organisers myself but many of them do not have the authority to make the decision. I decided to ask their bosses to help with my interviews. With Professor Kim's help, they were more than willing. An officer in Seoul City Council asked a president of the community care association, and they were then effective in helping with my interviews. Finally, the interviews were finished in the current scheme on the 26th November.

In addition, I visited day care centres, respite care, care homes, and attended a Care Assistance Training Course to see the reality of long-term care in Suwon and Seoul (total: 11 places). In residential care, Korea has a higher patient density per room than Scotland. There are few single rooms. Some places do not have proper locks on the doors. Most of them do not have a garden.

On the other hand, documentary data has been collected from the NHI in Suwon, the National Central Library and Yeunse

University. Moreover, professional people gave me documents related to long-term care.

There might be a question about the reliability of the data because it was based on single interviews. However, despite the single interviews, the contents of interviews fully contained almost real situations of interviewers because the interviews were repeated. In addition, family carers at home often ‘suffer in silence’ without sharing their problems with others. Therefore, they were pleased to be asked about their problems and answer honestly. Furthermore, I spent more or less 2 or 3 hours on each interview, even if the interviews were conducted for an hour, to get to know each other and build rapport with interviewees. Therefore, interviews were deeply conducted even if they were single interview. I asked if they could be in contact with me in the future for further questions. Therefore, whenever I needed to confirm their information, I phoned them and confirmed the information.

Data Analysis

The framework in this thesis provides the key questions of the interviews and ‘guides the analysis, indicating where, and on what, attention should be focused’ (Robson, 1993:377-8). The semi-structured interview schedule has been organised based on the theoretical framework, and the data on the diagnosis of dementia,

family care, social services in the community and residential care were organised according to how the culture and social policy affects the attitudes in each topic.

The process of data analysis starts with the recording and noting down of interviews. In other words, I also took notes in order to record the many contextual signs which are not reflected on tape. Thus, interviewees' moods, interview atmosphere and my reflections upon the interactions were noted.

Data management needed to be done before data analysis, although there is no clear-cut difference between data management and analysis. According to Marriam (1998), data management has three stages: data preparation, identification and manipulation. In the data preparation, all recorded interviews were transcribed and notes typed. Before data preparation, I listened to each interview all the way through and felt the first impression of the interviews. I concentrated on parts that I should write the transcript for, although the interviews were fully transcribed into a word document.

Regarding the identification of data, the interview transcripts were coded. Coding categorises data (Robson, 1993:386). Therefore, I read transcripts several times and categorised the data. The categories were organised into diagnosis of dementia, family care, social services at home and residential care as a theoretical framework. During the data categorisation, data was reduced without important information being lost. After the data management, I found important concepts and

arguments from the data. These data and findings are displayed in each chapter concerned. I provided the categories of the interview to the supervisor to get comments in order to increase the credibility of the research.

This study is based on family carers in Scotland and Korea. Interviews had been transcribed. Interviews in Scotland were written in English in the transcription. In the case of Korean interviews, they were typed in Korean for better understanding. After reading the Korean transcription, important and significant interview data were translated in English. It was not easy to translate Korean into English particularly in the expression of emotions. I do not want to alter the original meaning of their emotions. However, it was very difficult to find the right word or expression for their emotions. I looked back to the interview process then realised that it was important to make a note about the emotional part during the interview. Therefore, I will be cautious regarding interviewees' emotions in the interview and make a note about them in the future.

Ethical Consideration

According to the ethical principles for conducting research with human participants (British Psychological society), researchers must 'consider the ethical implications and psychological consequences for the participants in their research' (Robson, 1993:471). Interviews

should be planned and conducted with due consideration for all the interviewees' 'psychological well-being, health, value, dignity'. This means that the interview should respect interviewees' culture, age, gender and social background. These ethical issues can be embodied in the areas of informed consent, anonymity and confidentiality, protecting participants from harm and protecting researchers from harm (Lewis, 2003:70).

As regards informed consent, this study informed interviewees about 'the purpose of the study, how the data will be used, and what participation will be required of them, how much time is required and so on' (Lewis, 2003:67). I wrote a letter to inform them of the aim of the study, how I would use the data, how I would conduct the interview, the time the interview would take, and so on. This letter was sent with an extra envelope with stamp. When I received the participants' letters with their agreement to participate, I then phoned to confirm the interview time and place. Moreover, I again introduced my study purpose, and sought again their agreement to participate in the interview, and agreement to the use of the resulting data. I also asked them to confirm their willingness that the interview be recorded.

Anonymity and confidentiality should be promised in order to respect privacy (School of Social and Political Studies Research and Ethics Committee [SSPSREE]). A qualitative interview, in general, may access more sensitive information about interviewees (Yang,

2005:65). Therefore, the principle should be considered as follows: 'Anonymity means the identity of those taking part not being known outside the research team and Confidentiality means avoiding the attribution of comments, in reports or presentations, to identified participants' (Lewis, 2003:67).

In order to achieve anonymity and confidentiality, I changed the participants' names and avoided identifying their features. Anonymity and confidentiality have suggestions for data storage. Recording tapes and transcripts were not named in any report in order to secure confidentiality. The identifying information was stored anonymously and in a secure place. I transcribed the interviews personally and stored them in different folders. My computer needed a security number to log on; therefore, the data was secure. I changed the participants' names and some personal identity information in this study in order to achieve anonymity and confidentiality.

Interviewees should also be protected from harm (SSPSREE). Researchers have 'a primary responsibility to protect participants from physical and mental harm during the investigation' (Robson, 1993:473). An interviewer should ensure the participants' well-being and healthy conditions. The interviewer should consider carefully and provide special effects to protect interviewees from harm. To avoid harm, I stayed after finishing interviews and answered any doubts or curiosity from the interviewees. Moreover, I discussed general issues in Scotland and Korea at the end. This ending provided relief, solved

discomfort and satisfied curiosity in the participants. The interviewer should be aware of his/her role clearly; for example, it is not appropriate to give advice, nor to comment favourably or unfavourably on interviewees' decisions or circumstances beyond expressions of empathy (Lewis, 2003:69). The role of the interviewer was considered throughout the interview process.

The researcher was also not placed at risk. Some risks arose regarding transport and venues, etc. I searched the venues on a Google map and the bus numbers in advance. Moreover, I told colleagues about the interview times and locations whenever I arranged my interviews in Scotland and Korea. Sometimes, my colleagues picked me up at the interview place at a certain time.

I experienced one male interviewee who phoned me around midnight though I was asleep at the time. I subsequently found the atmosphere in the interviewee's house to be strange. For example, he lit many candles in the living room in broad daylight in May. For this reason, I was apprehensive about interviewing male interviewees. I thought I should tell a university colleague about the interview time and place for my safety. I was aware of the need for anonymity and confidentiality. Therefore, I indicated to interviewees in advance that I was being dropped off and collected by a colleague and that they could withdraw if they objected to this arrangement. All the interviewees accepted and agreed to this without any hesitation.

Moreover, my university colleague did not know their name but knew the area name of the interview place.

Chapter 3. Dementia Diagnosis in Scotland and Korea

The care of older people with dementia begins with the diagnosis of dementia. A diagnosis of dementia can be upsetting for older people. Yet, it can help them prepare their future care plan, financial and legal matters, understand their illness and behaviour, and progression of symptoms (Alzheimer Scotland, 2003:8; Connell et al., 2004:500). In addition, an early diagnosis of dementia is very important due to many benefits for family carers. For example, it provides understanding about the problems of memory or behaviour, making access to information and social services easier, encouraging adaptation and coping, helping for the future, and improving communication during health care visits (Connell et al., 2004:500). Moreover, previous studies show that differences in cultural and social policy affect the attitudes towards the understanding, diagnosis and treatment of dementia. This chapter, thus, explores the differences in understanding and diagnosis of dementia from the perspectives of family carers in Scotland and Korea. In addition, it investigates how health systems and cultures in the two countries affect the diagnosis of dementia differently.

Before the discussions of discovery of dementia symptoms, diagnosis and treatment, the health systems in Scotland and Korea will be introduced. This part, then, investigates the discovery of dementia

symptoms, diagnosis of dementia and treatment of dementia in Scotland and Korea. The Scottish case in each section will be introduced first and the Korean case will follow. After the demonstration of the sections, an analytical summary of this chapter is provided.

3.1 Health Systems in Scotland and Korea

Scotland

In the twentieth century, National Health Insurance was established and the Emergency Medical Services was set up during the war. After the war, there was a ‘national consensus’ about ‘what governments could and should do’ (Pascall, 2003:398). William Beveridge made plans for post war social security. Based on the Beveridge report, the Labour government and Aneurin Bevan, who was the Minister of Health, established ‘comprehensive health and rehabilitation services’¹¹ (ibid.). The National Health Services Act was passed and started in 1946 and 1948 respectively. The NHS has covered all the people and is free to use. It has been funded by general taxation rather than insurance contributions. In other words, the NHS is universal and

¹¹ Bevan ‘aimed to ‘universalise the best’ health care, in contrast to a Poor Law, minimum-level approach which favoured means-tested services for the poor, and which stigmatised those who used it’ (ibid. 398).

equal to all citizens. The NHS began with a leaflet, 'The New National Health Service', declaring that:

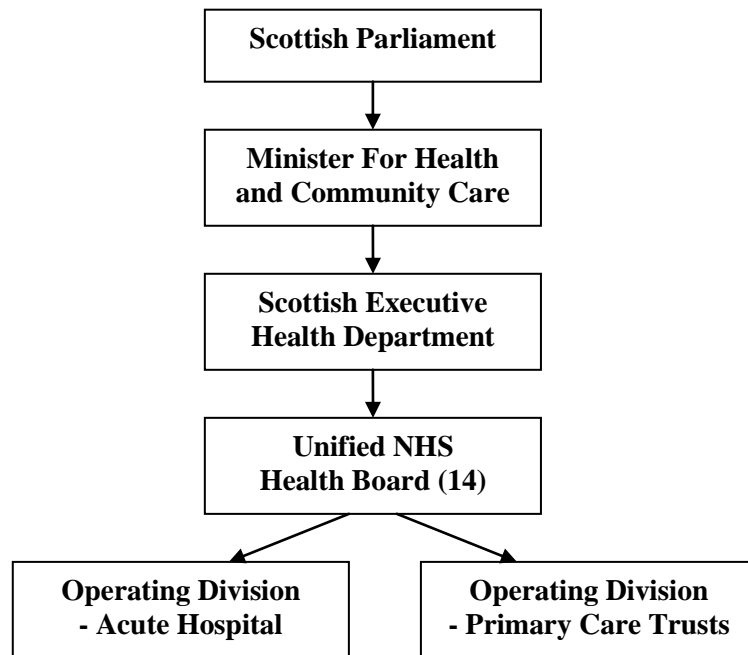
'It will provide you with all medical, dental, and nursing care. Everyone - rich or poor, man, woman or child - can use it or any part of it. There are no charges, except for a few special items. There are no insurance qualifications. But it is not a charity. You are all paying for it, mainly as taxpayers, and it will relieve your money worries in time of illness' (quoted in Webster 1998:24; re-quoted in Pascall, 2003:398).

The politicians have continued to state 'loyalty to NHS ideals', although Thatcher and Blair's governments tried to introduce market-oriented systems for healthcare (ibid, 2003). People in Britain also strongly believe that the NHS should be continued. The NHS still is a universal service for all without measuring ability to pay and the promise of a comprehensive range of services has been restated (Department of Health, 2000).

The NHS in Scotland is not significantly different from other parts of the UK but it has been developed differently in the structure and plan for an NHS based on Scottish needs. After devolution, the Scottish Executive (now Government) and the Scottish Parliament took over the role and accountability of the Secretary of State for

Scotland. Full legislative power for health was devolved in the Scottish Parliament. The Minister for Health and Community Care is accountable for all health policies and the management of the NHS. The responsibility for producing policies and administering them lies with the Scottish Executive Health Department. The NHS Boards are significant bodies accountable for local health care organisations, the funding, and health plans according to the needs of regions. In the Boards, there are operating divisions for secondary (acute hospital) and primary care (primary care trusts). Primary care trusts support the frontline of care in service delivery, strategy and improvement of care services. They have a duty on joint agreements of funding and service delivery between primary and secondary care. An acute hospital is responsible for the management of hospital services (Galloway, 2004:18-21). It results in the allocation of blocks of expenditure to the Scottish government. The Scottish Finance Minister (upon approval from the Government) divides up the funding between central health services, NHS boards and the NHS at local level (Ham, 2004:108; Galloway, 2004:14).

Figure 3- 1 NHS structure in Scotland



Source: Galloway, M. 2004, The ACP guide to the structure of the NHS in the UK, p.14

The Health Service is significant for older people with dementia and it is a starting point for them to face and solve the new problems in their life. Although there is no cure for dementia, early diagnosis and appropriate treatment help to relieve the illness and symptoms. Moreover, patients can prepare for the future and arrange support from family and services. The Scottish government, therefore, announced ‘Mental Health in Scotland Dementia: A National Priority’ in 2008 (The Scottish Government, 2008). It addressed the improvements in the early diagnosis and managements of people with dementia by March 2010. Each Health Boards estimate numbers of the dementia prevalence and make a target number to diagnose. Moreover, Health Boards provide strategy to achieve the target (ibid).

Korea

The Korean government introduced a health insurance law for citizens in 1976 and for government employees and private school teachers in 1979. In the same year, the government created a medical assistance programme for under the poverty line. National Health Insurance became a universal programme covering the whole population in 1989 in combination with the Medical Assistance Programme. The public dementia hospitals began to form in 1996. After the economic crisis, funds for services for wage earners and non-wage earners were combined into one in order to solve the financial and management problems in the NHI¹². The NHI funds completely combined in 2000. The Korean Government plan to increase the number of Public Dementia Hospitals in order to encourage early diagnoses of dementia and long-term care. Moreover, Korea developed simplicity and accuracy in instruments for examination of Dementia which started in 2006. The Minister of Health, Welfare and Family Affairs announced the ‘General Plan for Dementia’ in 2008 to achieve early diagnoses of dementia. It asserted a free diagnosis of dementia except a charge for MRI or CT scans, thus diagnosis of dementia was not totally free. It also announced vouchers for free dementia medicine for those in a low-income bracket (Ministry for Health, Welfare and Family Affairs (hereafter MHWFA), 2008).

¹² Korean Health Insurance funding had been administrated differently according to their occupations for example, monthly wage earners and non-wage earners who are mostly self employee.

Table 3- 1 Development of health system in Korea

Division	Name of Scheme	Ministry*	Authoritarian (~1986)	Democratization (1987~1996)	Economic crisis (1997~)
Health Insurance	National Health Insurance	MHWFA	- 1963 enacted but not a compulsory insurance - 1976 revised as a compulsory, a work place for more than 500 workers	-1989 expanded into all people	-1998 integrated management system of NHI Funds for wage earners with funds for non-wage earners
Public Assistance: Medical Service	Medical Assistance	MHWFA	-1977 enacted		

The Korean Health Security Programme is delivered through National Health Insurance and the Medical Aid (hereafter MA) Scheme. 3.7 per cent of the total population receives MA and 96.3 per cent of them are insured by NHI. NHI covers all Korean citizens including employees, the self-employed, and dependents of the insured. People in low income brackets are insured by MA.

The NHI provides mainly in-kind benefits which are medical treatment care and health screening benefits in the treatment of sickness or injury and disease prevention. The NHI provides free health screening services¹³ for the insured and their dependents who

¹³ 'The first step covers 23 items including consultation, oral cavity check-ups, chest X-rays, etc. The second confirmative test covers 28 items coming under 8 diseases including tuberculosis and diabetes. Eligible beneficiaries also can apply for examinations for 5 major cancers which are stomach, colon, breast, liver and cervix cancer. The costs of the cancer test are shared by the National Health Insurance Co-operation (hereafter NHIC) and the beneficiary. In case of stomach, colon, liver, and breast cancer, the NHIC covers 80% of the cost and the beneficiary pays the remaining 20%. The NHIC covers the total cost in case of the cervix cancer. The

are aged 40 or over biannually. However, the free health screening services do not include a dementia test. They also provide a refunding allowance, funeral expenses, compensation for an excessive co-payment and co-payment ceiling system. The co-payment ceiling system protects people who pay high co-payments. The co-payment limit is 2 million won within 6 months for inpatient, outpatient and pharmaceutical services. Further co-payments are paid by NHI. The NHI does not cover total free medical treatment. Inpatients are responsible for paying 20% of the total medical care charges but it excludes various examination charges which are not covered by NHI, meal charges and personal care charges. In addition, patients who stay in a room with less than six beds should pay an extra charge. The co-payment rate for outpatient services diverges according to the level of health care facilities and total amount of medical charges as the table shows.

NHIC has been putting much emphasis on its solicitation activities to promote health screening, especially of the self-employed' (NHIC, 2007).

Table 3- 2 Outpatient Co-payment		2,000 won = 1 pound
Type of Medical Institution	Location of Medical Institutions	Co-payment
Specialised General Hospital	All Areas	Total Amount of Consultation Fee + 50% of Total Health Care Costs
	Urban Areas	50% of Total Health Care Costs
General Hospital (more 100 beds)	Rural Areas	Exceeding 15,000 won: 50% of Total Health Care Costs
		Not Exceeding 15,000 won: 4,600 Won
Hospital (more than 30 beds) Dental Hospital Oriental Hospital	Urban Areas	40% of Total Health Care Costs
	Rural Areas	Exceeding 15,000 won: 35% of Total Health Care Costs
		Not Exceeding 15,000 won: 4,100 Won
Clinic Oriental Clinic Public Health Centre	All Areas	Exceeding 15,000 won: 30% of Total Health Care Costs
		Not Exceeding 15,000 won: - 3,000 won(aged less 65 years) - 1,500 won(aged 65 years and over)
Dental Clinic Public Health Centre (Dental)	All Areas	Exceeding 15,000 won: 30% of Total Health Care Costs
		Not Exceeding 15,000 won: - 3,000 won(aged less 65 years) - 1,500 won(aged 65 years and over)
Pharmacy	With Prescription	Exceeding 10,000 Won: 30% of Total Health Care Costs
		Not Exceeding 10,000 won: - 3,000 won(aged less 65 years) - 1,500 won(aged 65 years and over)
	Without Prescription	Exceeding 4,000 won: 40% of Total Health Care Costs
		Not Exceeding 4,000 won: - 1,400 won(Medicine for 1 Day) - 1,600 won(Medicine for 2 Days) - 2,000 won(Medicine more than 3 Days)

Source: National Health Insurance Co-operation, 2007.

MA is a public assistance scheme to secure the minimum livelihood of low-income households and help their self-help through providing medical services. Each local government selects the beneficiaries who meet the conditions that the MHWFA sets (see table 3-3). MA provides the same services as those in the NHI program. However,

patients in MA follow a fixed stage system, unlike the NHI. Firstly, they appoint primary care, such as a public health centre, clinic, dental surgery or oriental clinic to an outpatient. Secondly, they appoint secondary care, such as a general hospital, hospital, dental hospital, or oriental hospital for inpatients. In the NHI there is no fixed stage system, like that of MA.

Table 3- 3 Requirements of Receivers and Co-payment Rates in MA

2,000 won = 1 pound

Division		Type One	Type Two
Requirements	Receiver	Those unable to work as defined by the "National Basic Livelihood Security Act", Kwangju Democratic Rising Victims, Human cultural assets, Escapees from N. Korea, Persons of national merit, Victims of calamity, STD patients	Persons, other than Class I, as defined by the "National Basic Livelihood Security Act"
Co-Payment	Inpatient	Free (exclude meals, hotel fee and personal care charge)	15% Government can loan money for receivers when co-payment is over 100,000 won
	Outpatient	-0%	- Every visit: 1,000 won - Secondary or third medical institution: 15%

Source: Choi, S.J. & Jang, I.H., 2007:394.

The Korean government introduced free health screening for people aged 65 or over in MA in 1983. The government has expanded free health screening for those in a low income bracket who get income less than 120 per cent of the minimum cost of living since 2005. The health screening has two stages; primary health screening does initial tests in public health centres and secondary health screening offers

accurate and professional diagnoses in authorised hospitals. However, most private hospitals avoid providing free health screening for older people due to low medical charges, thus, authorised hospitals are mainly local authority hospitals or government hospitals.

To sum up, there are similarities and differences between health systems in Scotland and Korea. Firstly, there is a similarity on health policy which emphasises the early diagnosis of dementia in Scotland and Korea. Secondly, there are differences between their health systems. For example, Scotland provides free universal health services while Korea provides health services based on a means-test. Moreover, Scotland provides general funding of the NHS through taxation while Korea's health system is funded by an insurance system. It means that Scotland has a more egalitarian system than Korea. It provides free access for all citizens in Scotland, thus, the accessibility of the health system in Scotland is higher than in Korea.

3.2 Discovery of Dementia Symptoms in Scotland and Korea

The early recognition of dementia provides an opportunity for an early examination of dementia and treatment which can promote the function of older people with dementia and slow the progression of

the disease (Corner & Bond, 2004:143). Therefore, it is important that family members or older people with dementia recognise dementia as soon as possible. This section explains the carers' experiences related to the acknowledgment of dementia symptoms in Scotland and Korea. In detail, it demonstrates how the sufferers and carers react about dementia signs, who recognises, what the noticeable signs are, and when they notice.

Recognition of dementia symptoms as “Uncertain but Strange” in Scotland

Based on the interviews, most older people with dementia and their families in Scotland recognised dementia symptoms but they did not confirm the signs of dementia when they were first noticed. Miss C doubted her mother's dementia signs at first, even though she was a district nurse. Mr. D also noticed it but he was unsure about dementia.

“It started maybe 5 years ago. ... She was functioning perfectly well, understood perfectly well it was just you know she knew what she wanted to say but she started having difficulty getting a right word. After little while we didn't know whether it was or wasn't dementia” (Miss C).

“Just my mother died 3 years ago this April. About four or five months after that I noticed something different, he was making a lot of mistakes, not remembering. I thought something wasn't right” (Mr. D).

Who then notices the signs at first? By and large, family carers and older people with dementia do. For example, spouses and children, who live with older people with dementia or have regular contact, recognise the initial signs of dementia. In addition, sometimes, people with dementia feel something wrong with themselves. Mrs. M's mother noticed her forgetfulness by herself. Her mother was wondering whether the symptoms were dementia or not. Mr. J's wife also recognised her dementia symptoms.

"About 4years ago, well... she just started to notice she was getting forgetful. I started to notice things like that she was forgetting to make tea or through things like that" (Mrs. M).

"My wife was the person who diagnosed her own illness" (Mr. J).

Likewise, people know dementia from characteristic symptoms. In other words, carers find various symptoms about dementia such as repeating, forgetfulness, delusion, etc. Mrs. F and others observed various symptoms as below:

"I noticed he would ask me things twice. He (husband) came through to say "Would you like a cup of coffee?" and go back "Would you like a cup of coffee?" So I caught it very, very early" (Mrs. F).

"I just noticed that she (wife) was not remembering immediate past dates." (Mr. G).

"Just all of sudden, she said the lady next door her house come in when she was not there and stole her money. The lady next door is very disabled and she has two walking sticks. I thought very bizarre. She was never like that." (Mrs. L).

On the other hand, there can be a misunderstanding of symptoms. For example, carers can confuse the symptoms of depression and dementia because their symptoms are very similar (Alzheimer's Society, 2009). For example, Mrs. A's mother used to be depressive, particularly after specific accidents or crises, thus, she mistook the symptoms of dementia as signs of depression. Moreover, carers who did not live together with older people with dementia could not recognise the symptoms easily. In this situation, the discovery of dementia happens by chance. Mrs. A, who lived apart from older people with dementia, faced a crisis when they were on holiday.

"She was diagnosed three years ago, July. But think she had it for a year prior to that. I just thought she was depressed after my father died. And then I took her away for a weekend in my Caravan. And she went out overnight in her nightdress. I thought something was wrong then" (Mrs. A).

Overall, according to the interviewees in Scotland, they tended to recognise dementia signs as abnormal at an early stage. Firstly, Scottish carers in this study noticed 'something wrong' with their relatives in the beginning of dementia although they were not certain about dementia. Furthermore, they did not mistake the recognition of symptoms as just signs of normal age, although one carer misunderstood dementia symptoms as depression as can be seen in the Mrs. A case. Secondly, Scottish carers and sufferers in this study

would recognise the symptoms in the early stage as can be seen in Mrs. J's case. Most of them described the symptoms, for instance, forgetting, difficulty with finding right words and repeating questions, which can be regarded as signs of the initial stage of dementia.

Recognition of dementia symptoms as “Just a Normal Phenomena of Old Age” in Korea

In Korea, family carers tend to delay the diagnosis of dementia because of ‘misattribution of dementia symptoms to a normal happening in ‘old age’ (DH, 2009:25). In other words, Korean carers tend to recognise dementia signs or symptoms late because of the lack of knowledge about early signs of dementia. Dementia in Korea used to be known as ‘MangRyung’ or ‘NhoMang’, which meant that a person’s soul dies or loses (Korean Dictionary, 2009). Also, ‘MangRyung’ or ‘NhoMang’ has been recognised as normal forgetful or strange behaviour presented in old age. In the case of carers in Seoul, Miss N1 said that her father lived with her mother but he thought the signs of dementia were a normal and anticipated part of ageing. Mr. M1 noticed dementia symptoms but he believed it was the normal ageing process.

“Mum got the dementia about six years ago. In the beginning, she was in hospital and almost dead. At the time, I wasn’t here (she was in Japan). Since then she had developed her dementia but my father (who passed

away) thought that she was just 'MangRyung' for old age" (Miss, N1).

"My father and I knew she got dementia but we thought it was a normal ageing process" (Mr. M1).

Mrs. L1 found her mother-in-law acting strangely but didn't recognise it was dementia.

"I have lived apart from my mother-in-law. ... She said that she lost something and somebody stole it. ... She said that she went out for lunch with somebody, but I knew she stayed in her room all day. I recognised she was not very well but I didn't know it was dementia signs" (Mrs. L1).

Meanwhile, carers in Suwon have similar attitudes towards dementia symptoms. Mrs. L2 did not know that her mother had dementia. She even believed anything that her mother told her, even if it was delusional.

"Mum started dementia six years ago. ... One day, she said to me young man downstairs came and watched for stealing and lost something. At first, I said to her 'you shouldn't suspect the young man without evidence'. Later on, I came to believe her story. ... I didn't know it was an illness. I noticed her signs but I assumed she was too old to loss her memory" (Mrs L2).

Previous studies show that the condition of dementia can be stigmatised in the community, thus, the problems are intentionally hidden to avoid community awareness (Mahoney et al., 2005:788; Corner & Bond, 2004:150). In Seoul, Mr.C1's experience was that his

family hid his mother's dementia signs or symptoms from him when he came back from abroad. One day, a member of the community recommended he should go to hospital with his mother for an examination.

"I came back from abroad in 2002. At that time, she (mother) already had dementia but my family hid it from me. ... In the past, people tried to hide dementia persons in their family. But a pharmacist in my village suggested me to bring her to hospital and said that the medicine was good in these days so must not hide it" (Mr.C1).

If there is a strong stigma attached to dementia, Korean carers would not want to discuss the symptoms of dementia with other people. However, in Suwon, Mr.D2 found his mother's dementia symptoms and discussed them with his neighbour.

"In the beginning, I didn't know she got dementia. I didn't think it was strange. I thought it was natural ageing. She talked deliriously and did strange behaviour. ... I talked to other people about her behaviour then they said it was dementia and recommended me to go to hospital to check dementia" (Mr.D2).

Some studies show that Asian people attach stigma to dementia which is just one of many mental diseases (Mahoney, et al., 2005). This study finds many carers get advice on dementia diagnosis from community members or neighbours. Likewise, there has been a change of attitudes towards dementia in Korean society.

According to the family carers in Seoul and Suwon, most cases had recognised dementia through a spouse, children or neighbour, as seen above. Sometimes, older people with dementia themselves notice that something is strange with their memory, speech or behaviour. There was only one case where an older person with dementia noticed her dementia in Korea. Mr. B1's wife, who lived in Seoul, felt strange herself. She recognised that it was difficult to speak in the beginning.

“In 1997 or 8, she said that whenever she went to her friends gathering meeting she could not speak. In 2001, she really wondered if something wrong with her” (Mr. B1).

Regarding dementia symptoms, they are similar to those of Scottish older people with dementia, such as memory problems, sleeping, repeating, paranoia, and incontinence and defecation problems. According to interviewees in Seoul, the symptoms were various but some carers experienced a very dangerous crisis as a fire broke out due to their forgetfulness.

“My grandmother said somebody took her money. She repeated it again and again. She also did not eat food and even hid it so it went worse. What a pity! She often forgot she put something on fire (Mr.M1).

“She put her kettle on fire to drink coffee but she forgot. She could make fire so I could not go anywhere. I did not know she had dementia, although other people saw her then said it might be dementia” (Mr.J11).

In Suwon, there are many examples in relation to the symptoms and they have developed little by little. Mrs. C2 and Mr.H2 have experienced the progression of dementia symptoms.

“His (father in law) memory has been blurred from November last year (2006), unconsciously incontinence from January (2007). He also has paranoia. He said his wife (died long time ago) came and disappeared so he sought all over house for her. He also doesn’t sleep at night” (Mrs. C2).

“The symptoms of dementia came out very slowly. 4 or 5 years ago, my aunty lost her dentures several times. 3 years ago, she lost her way more or less 30 times” (Mr.H2).

When was dementia discovered? For a description, first of all, it is more useful to know the Korean family structure. It has changed from extended family to nuclear family. The mean size of a household has been reduced from 5.0 persons in 1975 to 2.9 persons in 2005 and more than 90 per cent are nuclear families in 2005 (Korea National Statistical Office, 2007). Some family carers who are children of older people with dementia find dementia when it has already progressed quite a bit. In Seoul, Miss. N1’s mother’s dementia symptoms appeared in hospital but nobody took them seriously. Miss Han came back from abroad and found her mother already had dementia.

“My mother went to hospital 6 years ago, the symptoms appear in the hospital but my father did not take it seriously. My parents lived on their own, so nobody in my family knew she got dementia” (Miss.N1).

In Suwon, Mrs. J2's mother moved to her house three years ago. She did not know her mother had dementia but she had recognised her mother's dementia symptoms soon after moving to her house. Mrs. N2's mother went to hospital then her dementia symptoms noticeably came out.

"My sister didn't want to live with mum any more so I brought my mum. We have lived together the year before last... Mum repeated over and over ... She hid something and forgot where she put it." (Mrs. J2).

"15 years ago, she showed her dementia signs. She doubted her neighbour and her stepson stole her money. I did not know it was dementia. In 2005, she broke her back and went to hospital. ... She was very ill so I did not notice she gets dementia but other patients and their carers said she might have dementia" (Mrs. N2).

As can be seen in the above description, firstly, Korean carers tended to believe signs of dementia are a natural part of old age, thus, did not pay attention to the symptoms. Some of the carers stated that dementia might have started more than 10 years ago when they looked back. The carers misinterpreted the various symptoms that were observed, particularly early dementia signs. In some cases, particularly that of Mrs. L2's mother, the symptoms of dementia were obvious, but Mrs. L2 and her siblings did not recognise them due to a lack of knowledge on dementia. Secondly, Korean carers became aware of dementia signs when they became moderate or severe. In detail, the carers became progressively uneasy about dealing with the symptoms, and eventually they realised that 'something wrong with older person'.

Last, but not least, there was one case mentioned about the stigma attached to dementia. However, stigmatic attitudes towards dementia have been changed according to the interviews. Moreover, the stigma seems to be caused by a lack of knowledge rather than cultural reasons.

3.3 Diagnosis of Dementia in Scotland and Korea

After the recognition of dementia symptoms, what is the response of family carers or patients? Which factors affect a diagnosis of dementia, especially an early diagnosis? There can be many factors that affect people's behaviour and decisions. In detail, carers may not immediately use a diagnosis of dementia because of time-constraints, expensive cost of the process, lack of information or knowledge of where to go for medical consultation, the unwillingness of people with dementia to cooperate, and disagreements among family members (Teel & Carson, 2003; Connell et al., 2004:500).

Among the barriers, national health systems might be a crucial factor because the expensive cost of the process and lack of information for medical consultation can be relevant with health care systems in different countries. Scotland and Korea have different health service systems. While the latter has the Health Insurance System which charges co-payment, the former has the NHS which is

free at the point of use. Therefore, older people with dementia have different accessibility to diagnosis between the two countries. Furthermore, GPs usually refer their patients to a specialist in Scotland whilst there is no GP or family doctor system in Korea, thus, patients or family should find out where to go for help in Korea.

In this section, the diagnosis system for dementia is explored. Also, this part demonstrates the process of diagnosis and examines what facts encourage or discourage a diagnosis of dementia, and in particular investigates how the health system affects a diagnosis of dementia.

On the other hand, disagreements among family members may result from cultural beliefs or a lack of knowledge of dementia. In previous studies (Phillips, 1993; Hinton *et al.*, 2000), dementia was recognised as a mental illness, thus, people avoided a diagnosis of dementia. This section will also explore whether cultural influence exists or not.

Dementia Diagnosis in Scotland: Immediate Medical Consultation after Signs

As mentioned above, family carers play a significant role in the diagnosis of dementia. They can encourage or discourage a diagnosis of dementia. Their reaction to dementia symptoms is a turning point for diagnosis. People are not aware to the symptoms of dementia but

they start to feel strange. After they recognise the dementia symptoms, they contact a relevant GP to discuss the symptoms of dementia. Sometimes their children contact the GP in advance, like Mrs. L. Spouses also contact their GP in order to consult about their partner's signs of dementia. Most cases tend to be handled by carers of older people with dementia and they discuss the symptoms with the GP. Based on these processes, there is the meeting with patients.

“(After she recognised her strange behaviour) I manage to get in touch with my mum’s GP and she managed to get mum to go to the Royal Victoria and took her up to Royal Edinburgh to get assessment. They got a diagnosis of mild dementia” (Mrs. L).

“I mentioned it (memory problems) to Dr. M. And she asked her few things. From the responses, she thought there might be some slight memory lost. So she would send to West General to see Dr. A. who’s in charge of some department to do with lost memory and that” (Mr. G).

Sometimes, older people with dementia themselves are wondering about their signs of dementia and directly meet their GP. Mrs. M's mum and Mrs. J went to see their GP when they found ‘something happening to my memory’.

“(After she noticed her forgetfulness) She (mother) went to go to Doctor herself and said ‘I think something happening to my memory’. So then she was referred to Royal Victoria Hospital and they said she had a vascular dementia” (Mrs. M).

“My wife diagnosed herself 4 years ago and went to see the Doctor” (Mr. J).

However, older people with dementia may defer making a decision on dementia diagnosis because of their reluctance and fear. The husband of Mrs. B did not want to go to see the family doctor.

“4-5 years ago, I could think there was a problem he was forgetting. But he didn’t acknowledge his problems. He didn’t think he had problem with his memory. In first instance, I went to family doctor on my own without his knowledge. ... I didn’t like do it because it was sort of going behind his back. From there, the doctor suggested that he would go to memory clinic.” (Mrs. B).

Sometimes the process of diagnosing dementia can be distressing for older people. According to Miss. C, the diagnosis process for her mother took six months. Her mother had a mini-stroke but there was no medicine available for her dementia and she found it very distressing so she consulted her doctor about stopping the examination.

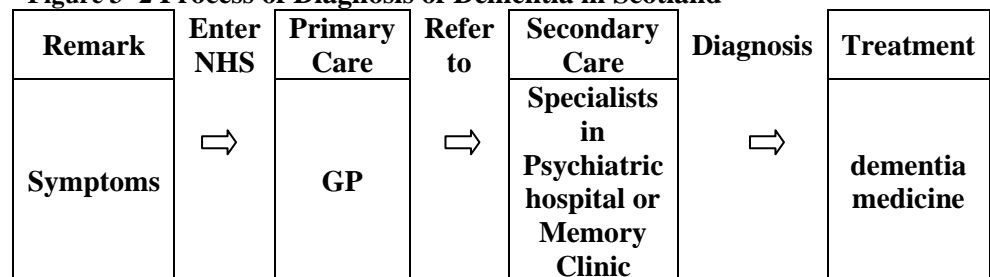
“The process of diagnosing dementia took 6 months. ... She find the process of diagnosis is quite distress for her. ... She went to GP and explained how she found it distressing to go to this test because there isn’t any treatment for her. “Was it necessary?” GP said “if you don’t want to go that’s fine”. She can step out the monitoring” (Miss C).

In Scotland, the diagnosis of dementia is processed as in figure 3-2. In general, sufferers experience two steps in health care services for diagnosis. First of all, people with doubts contact their relatives’ GP with symptoms of dementia. Secondly, the GP refers to specialists,

particularly doctors in memory clinics or psychiatric hospital, in secondary care in order to examine dementia. Finally, their relatives diagnose their dementia.

Scottish carers did not experience difficulty in accessing health services and finding where to go in the NHS system. A GP arranges the next step for acute assessment if it is necessary. Therefore, most carers directly contacted their relatives' GPs after they recognised the symptoms. A GP has a gateway role in the diagnosis of dementia in Scotland. It implies the importance of the role of GPs in the diagnosis of dementia. In this study, GPs encouraged the diagnosis of dementia rather than discouraged.

Figure 3- 2 Process of Diagnosis of Dementia in Scotland



In Scotland, most carers immediately contact their relatives' GP whenever they recognise any symptoms. Some of them may not recognise dementia owing to misunderstanding the symptoms, as can be seen in the case of Mrs. A who thought her mother had depression. However, when she also recognised the signs of dementia, she directly arranged a meeting with her mother's GP. Likewise, most older people with dementia can instantly examine the disease. According to

the table, 13 out of 14 carers said that older people with dementia were diagnosed in the same year their symptoms appeared.

Table 3- 4 Year of Diagnosis of Dementia in Scotland

	Carer	Older people with dementia	Kinds of Dementia	Dementia Level	Date of Diagnosis (symptom)
HI	Mrs. A	Mother (75, F)	Alzheimer	Severe	2003 (2002)
	Mrs. B	Husband (79, M)	Alzheimer	Moderate	2001 (2001)
	Miss. C	Mother (82, F)	Vascular	Moderate	2001 (2001)
	Mr. D	Father (85, M)	Alzheimer	Moderate	2003 (2003)
	Mr. E	Mother (77, F)	Alzheimer	Moderate	2003-04(03-04)
	Mrs. F	Husband (75, M)	Alzheimer	Moderate	2000 (2000)
	Mr. G	Wife (77, F)	Alzheimer	Moderate	2000 (2000)
LI	Mr. H	Wife (80, F)	Alzheimer	Severe	1999 (1999)
	Mr. I	Wife (78, F)	Alzheimer	Severe	1996 (1996)
	Mr. J	Wife (75, F)	Alzheimer	Moderate	2002 (2002)
	Mrs. K	Mother (79, F)	Alzheimer	Moderate	1993 (1993)
	Mrs. L	Mother (83, F)	Alzheimer	Moderate	2001 (2001)
	Mrs. M	Mother (93, F)	Vascular	Moderate	2002 (2002)
	Mrs. N	Mother (82, F)	Alzheimer	Moderate	1996 (1996)

As described above, there are some factors to encourage or discourage dementia diagnosis in Scotland. Firstly, early noticing of the signs of dementia, free access and the GP referral system promote early diagnosis of dementia. Scottish carers tended to notice the symptoms early and they directly reacted to arrange a meeting with a GP. Free access to the NHS and GP referral system helps to diagnose dementia early. There is no hesitation with medical consultants when GPs are at the start due to free access. In the Scottish diagnosis system, the GPs role is crucial, because if they deny or don't recognise the symptoms of dementia it could lead to a delay in the diagnosis of dementia. However, GPs in this study were not a barrier to the diagnosis of dementia. GPs help the carers and older people with dementia to be

referred to a specialist directly. Therefore, carers and older people with dementia in Scotland in this study have no barrier, and in particular regarding not knowing where to go for help to diagnose dementia. Secondly, this study found that an older person with dementia could cause a delay in the diagnosis of dementia because of fear and reluctance. Regarding disagreements in the family, there were not any family disagreements about the diagnosis of dementia in Scotland. A lack of knowledge could lead to a fear of dementia. Therefore, consultation with an older person with dementia is important and it should be provided carefully.

Dementia Diagnosis in Korea: Delay of Medical Consultation after Signs

Dementia carers tend to believe that dementia is a normal ageing process, and they do not search for a diagnosis or cure (Corner & Bond, 2004:148). Most carers in Korea don't recognise the disease and this leads to a delay in the diagnosis of dementia. Moreover, they do not search for medical consultation immediately even if the symptoms are observed. Generally, it is not until they face a big crisis owing to the full development of dementia symptoms that they visit a hospital.

In Seoul, Mr.C1's mother had dementia-related signs in 2002 but he and his family did not contact doctors or professionals to

consult. Even the village pharmacist recommend them to visit a hospital for a medical consultation. After a while, the dementia symptoms were aggravated, for example, she had a head operation last summer but did not remember and acted dangerously with her wound, then it became clear that she had dementia. He found a dementia prevention centre in a KD village newspaper. Finally, his mother got a diagnosis of dementia after Mr.C1 visited the dementia prevention centre in the Health Care Centre.¹⁴

“My mum ... fell down on the floor. ... A doctor controlled the bleeding and operated on her. What a surprise, my mum didn’t recognise the surgery. Before the wound didn’t heal up yet, she washed her hair. Soon I visited the Centre for the Prevention of Dementia in K-Dong and knew my mum got sick of dementia” (Mr.C1).

Miss. N1’s mother lost her ability to chew in 2007 but had a diagnosis of dementia in 2004. In other words, she got her diagnosis when she was already in the severe stage of dementia. According to Miss. N1, her father’s lack of information on dementia resulted in the delay of her mother’s diagnosis. Her father regarded the signs as a normal feature of ageing.

¹⁴ The government set up ‘the centres for counselling and report of dementia’ in public health centres according to the ‘the 10 year plan for the elderly with dementia’ in 1996. This centre was established for the prevention and early diagnoses of dementia. Sunwoo argued that the centre had a series of problems to be tackled, including the shortage of specialised counselling nurses and of other services linked with counselling (Sunwoo, 2001:16-17). Moreover, most older people were not aware of it, for example, only 24.9 per cent of them knew about the centre for dementia counselling. Moreover, only 1.7 per cent had used or were using the centre (Jeung et al., 2005:513).

“If my mother had gone to the hospital earlier, her situation would have been good. ... Only the two old parents lived together and they don’t know the disease. This made the situation worst. ... When I came back from abroad, she already was a serious case” (Miss. N1).

A lack of medical service information misled and this meant that time was wasted on the route to a diagnosis of dementia. Mr. B1’s wife had a diagnosis of dementia in 2001. In the beginning, she recognised ‘something was wrong with her’ and had a CT. They did not know where to go with the CT result. They visited three hospitals, then they diagnosed dementia.

“The disease might start in 1998, I think now... I confirmed it in the late 2001. The patient herself felt strangely. She took the result of CT. What was a big problem was that we didn’t know treatment of psychiatry. So we wondered where we went. ... we visited a hospital in affiliation to the University of J and finally knew, “this is dementia!”.” (Mr.B1).

In Suwon, Mrs. L2’s mother lived alone and nearly started a fire due to her forgetfulness. One day the landlord requested Mrs. L2 and her sisters take their mother. However, they did not recognise the symptoms of dementia. Mrs. L2’s mother moved several times from daughter to daughter due to her behaviour problems. The problems created many conflicts between mother and daughters owing to their lack of knowledge or recognition of dementia. Finally, the sisters took their mother to hospital where she was diagnosed with dementia at a severe stage.

“We had no idea of dementia at all. When we went to the B Hospital, her situation was very bad. In our case, ... the symptoms were getting worse because her daughters took care of her in rotation. Each daughter looked after her very well at first but gradually there were conflicts between them, finally the conflicts resulted in fighting. In her daughters’ house, it was difficult that she didn’t rest and the dementia was worse” (Mrs. L2).

According to Mrs L2 and others, the lack of information about dementia created a delay on the diagnosis of dementia. It also influenced the development of dementia rapidly.

Some carers found dementia through the diagnosis of another illness. In Seoul, Mr. D1s mother was very ill. He took her to a general hospital for a CT and endoscope. Finally, she got a diagnosis of dementia and gallstones (kidney stone).

“I thought my mother was very unusual, when my family (include mother) tried to have travelling on the second of August 2007. The (Kidney Stone) symptoms discovered two or three days ago. We quickly went to hospital for examining her body. I knew after exam of brain scan and CT, she was suffering from gallstones as well as dementia” (Mr. D1).

In Suwon, Mr.F2’s mother had high blood pressure and her brain vessels were nearly ripped. Mr.F2 took her to hospital in order to get medical treatment. In the hospital, her dementia symptoms were obvious, and as a result, Mr.F2 took his mother to neurosurgery to do an MRI.

“My mum had Vascular Dementia by cerebral infarction. On the way to Seoul, my mum phoned, “I am dizzy and often sit down plump.” ... So the hospital took emergency measures. In the situation, my mum was strange. ... I thought she did because she lost her energy. She was out of hospital because she made a disturbance in the hospital. ... so I pushed her to take MRI. The examination told she was already serious symptoms of dementia” (Mr.F2).

There is an issue regarding the affordability of dementia diagnosis in Korea. Korean health services are divided into the NHI and MA. The NHI provides free health screening services for the insured and their dependents who are aged 40 or over biannually. However, the free health screening services do not include a dementia test. Moreover, NHI uses co-payments, although the co-payments are limited at 2 million won within 6 months for inpatients, outpatients and pharmaceutical services, and further co-payments are paid by the NHI. Moreover, MA also did not provide the free screening services for dementia in 2007.

In Seoul, Mrs. H1 knew her mother had dementia symptoms but she did not treat it seriously. However, her mother moved to her house and her wandering about became a problem. Her mother lost her way several times, but she did not diagnose dementia immediately even if Mrs. H1 recognised. Mrs. H1 concerned about expense of diagnosis, eventually, she got an opportunity to get free diagnosis of dementia for her mother.

“I decided to take care of my mum in my house last year. ... After the circumstance changed, the symptoms of dementia suddenly grew worse. ... It was very difficult... One day a nurse, who was a member of domiciliary care team in my Catholic Church, told me that the Seoul St. M Hospital was providing free medical treatment for dementia for elderly people more than 65 years old” (Mrs. H1).

High costs for dementia diagnosis can lead to the postponement of a diagnosis, especially in lower income groups. Lower income groups feel a big burden to pay if they needed a special examination such as an MRI or CT, whereas the expense does not matter to higher income groups.

“My friend is a specialist in dementia in KD hospital, so I brought her in this hospital to diagnose. The examination fee is just ₩830,000 (£415). It is not expensive” (Mr.E1).

“Three years ago, dementia was found through an MRI for which 100,000 won (50 pounds) was spent. It is very expensive to the poor people. Furthermore, the bus fare to a hospital is added” (Miss. N1).

In Suwon, Mrs. I2’s mother got diagnosis for dementia, even though it was expensive, to qualify for long-term care services.

“Dementia was contracted two years ago. ... (When was the diagnosis of dementia?) Last year. My situation is very bad after my husband died last year. I would like to take her in free residential care for elderly people with dementia, so I tried to get a diagnosis of her dementia even if it was expensive” (Mrs. I2).

Some carers said that their relative with a dementia diagnosis qualified for services or benefits. There are cases of this in Seoul and Suwon, especially among lower income groups, because they need to suffer from dementia in order to be entitled to a free service.

“Anyway, due to diagnosis of dementia, I can use short-term care service. As you know, the service can be used only with diagnosis with dementia” (Mr. M1).

“I tried to examine whether dementia was contracted for using care homes. At first, a doctor was reluctant to decide my mum’s illness as dementia. Finally, the doctor did and it took two years” (Mrs. N2).

On the other hand, some people in higher income groups in Suwon had a diagnosis of dementia to use long-term care services.

“My father-in-law was diagnosed with dementia last year (2006) because the pilot long-term care scheme required certification of diagnosis of his dementia” (Mrs.C2).

The dementia diagnosis process in the Korean health care system is divided into two; the NHI and MA, as mentioned above. According to the health care system in Korea, MA provides two steps like Scotland, whilst the NHI does not have a strict step system. Carers in a low income group explained that they visited public health centres and were then referred to specialists in authorised hospitals for an acute assessment of dementia.

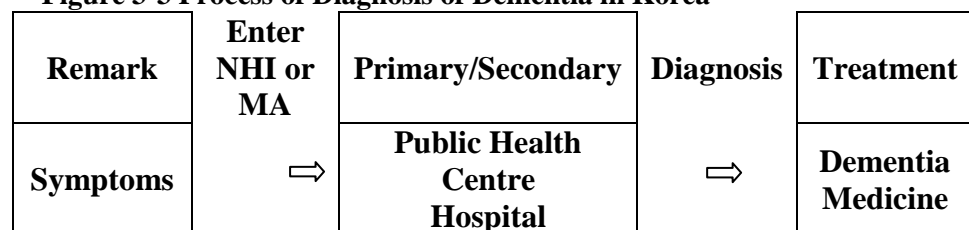
“There were two examinations of dementia. One was from the Public Health Centre and the other was from an authorised hospital” (Mr.H2).

On the other hand, recently the MHWFA introduced a dementia centre in public health centres, thus, a carer in a higher income group visited the centre to check his mother’s dementia then got referred to a special list.

“I went to the Department for Prevention of Dementia in the Public Health Centre for advice and got a diagnostic test in the Kandong Sacred Hospital” (Mr.C1).

However, most carers in higher income groups directly contacted specialists. Therefore, they struggle to find where to go for a diagnosis of dementia, as seen in the Mr.B1 case.

Figure 3-3 Process of Diagnosis of Dementia in Korea



Not: MHI: Medical Health Insurance, MA: Medical Assistance

Most older people with dementia in Korea diagnose their dementia later. Moreover, the majority did not recognise the early symptoms of dementia. Therefore, the diagnosis of dementia had been delayed. Many of them diagnosed when they were already at the moderate stage. In addition, some carers recognised the dementia symptoms

early but did not diagnose immediately, in particular Mr. E1 and M1 stated that they knew their relatives had dementia before diagnosis but did not go to hospital immediately after recognition.

People in Seoul seemed to get a diagnosis earlier than people in Suwon. The average period¹⁵ from the recognition of dementia symptoms to diagnosis shows that higher income groups tended to have a shorter period than lower income groups. It implies that the economic burden of diagnosis could delay their diagnosis of dementia, although it is difficult to generalise. People in lower income groups have to pay for an MRI or CT scan for a more exact examination. The system, thus, may discourage the people in lower income groups to diagnose dementia earlier than others. In addition, many carers in lower income groups stated that they diagnosed dementia when they qualified for social care services. The expense of a diagnosis affects the delay of a diagnosis.

It shows that in some cases, dementia is diagnosed in order to entitle the patient to long-term care services. Some people in higher income groups in Suwon had a diagnosis recently owing to the access of services. However, long-term care services do not cover the

¹⁵ Average period from the year of recognition of symptoms to the year of diagnosis of dementia

		Year	
Seoul	Severe	Higher	1.0
		Lower	2.5
	Moderate	Higher	3.75
		Lower	4.4
Suwon	Severe	Higher	3.3
		Lower	3.8
	Moderate	Higher	2.75
		Lower	5.0

expense of a dementia diagnosis; thus, people delay a diagnosis of dementia until the time when they desperately need the services. In fact, the entitlement of long-term care services demands moderate or severe dementia, thus, carers wait until their relative's dementia has developed to the moderate or severe stage.

Table 3- 5 Year of Diagnosis of Dementia in Korea

		Carer	Older person with dementia	Kinds of Dementia	Dementia Level	Year of Diagnosis (symptom)
S E O U L	H I	Mrs. A1	Mother (82, F)	A 1)	Moderate	2005 (02 or 03)
		Mr. B1	Wife (75, F)	A	Severe	2001 (1998)
		Mr. C1	Mother (80, F)	V 2)	Moderate	2007 (2002)
		Mr. D1	Mother (86, F)	A	Moderate(bedridden)	2007 (04 or 05)
		Mr. E1	Mother (78, F)	A	Moderate	2006 (1999 or 2000)
		Mrs. F1	Mother (90, F)	A	Severe	1997 (1997)
		Mrs. G1	Father (91, M)	V	Severe (bedridden)	1997 (1997)
	L I	Mrs. H1	Mother (83, F)	A	Moderate	2006 (2000)
		Miss. I1	Mother (80, F)	V	Severe (bedridden)	2004 (2002)
		Mr. J1	Wife (75, F)	V	Moderate	2007 (04 or 05)
		Mrs. K1	Aunt (90, F)	V	Moderate(bedridden)	2006 (1997)
		Mrs. L1	Mother in law (83, F)	A	Moderate	2006 (2004)
		Mr. M1	Grandmother (88, F)	A	Moderate	2007 (2005)
		Miss. N1	Mother (80, F)	A	Severe (bedridden)	2004 (2001)
S U W O N	H I	Mrs. A2	Husband (86, M)	A	Moderate	2007 (1999 or 2000)
		Mrs. B2	Husband (77, M)	V	Moderate	2004 (1997)
		Mrs. C2	Father in law (89, M)	A	Severe	2007 (2006)
		Mr. D2	Mother (88, F)	A	Moderate	2007 (2002)
		Mrs. E2	Mother in law (80, F)	A	Severe	2001 (2000)
		Mr. F2	Mother (82, F)	V	Moderate	2003 (2003)
		Mrs. G2	Mother in law (78, F)	V	Moderate	2006 (2003)
	L I	Mr. H2	Aunt (79, F)	A	Severe	2007 (2002)
		Mrs. I2	Mother (88, F)	A	Severe	2006 (2005)
		Mrs. J2	Mother (76, F)	A	Moderate	2005 (1995)
		Mrs. K2	Husband (85, M)	ARD 3)	Moderate	2005 (2005)
		Mrs. L2	Mother (82, F)	A	Severe (bedridden)	2004 (2001)
		Mrs. M2	Mother (78, F)	V	Severe (bedridden)	2004 (2004)
		Mrs. N2	Mother (77, F)	V	Severe (bedridden)	2007 (1997)

Note: Kinds of Dementia, 1) A: Alzheimer 2) V: Vascular 3) ARD: Alcohol related dementia

To sum up, firstly, a lack of knowledge on dementia results in the delay of a diagnosis of dementia in Korea. Older people with dementia in Korea diagnose dementia when they are already in the moderate or serious stage in this study. Kim's study (2002) also shows that 70 per

cent of patients visit a hospital to diagnose dementia and they are already in the moderate or serious stage due to a lack of knowledge on dementia. This study shows that almost all family carers in Korea have a lack of understanding of dementia and its symptoms, and as a result, it delays a diagnosis. Secondly, carers in Korea search for medical information themselves; thus, a lack of information on medical services discourages a diagnosis. Thirdly, the financial burden also has an influence on putting off a diagnosis. Unlike the NHS, the NHI system has co-payments; therefore, the financial burden influences the delay of a diagnosis. If older people with dementia have knowledge of dementia and can afford it then they consult directly with a specialist, therefore it could diagnosis in short period and earlier in Korea.

3.4 Treatment of Dementia in Scotland and Korea

Effective treatments in early stage of dementia tend to hold off dementia symptoms; for example, memory function and reduced anxiety for their relatives (Milne et al., 2005:449). It benefits older people with dementia as well as their carers. The control of dementia symptoms influences the carers' ability to care. It, thus, explores the

carers' reactions or understanding of the process after diagnosis, and carers' attitudes towards treatment, particularly medicine.

Treatment of Dementia in Scotland: No Cure but Useful

There can be various responses after a diagnosis of dementia. Some carers may be relieved to know their relatives' diagnosis of dementia. Mr. E felt relief after a diagnosis of dementia and became closer to his mother. However, some of carers are upset over their relatives' dementia and regret their actions.

*"If I'd known I would never move to far away (Cries)...
But you can't see what is going to happen" (Miss C).*

Family carers do not want to disclose older people with dementia due to it causing depression (Connell et al., 2004:501). Some Scottish carers feel reluctant to inform of a diagnosis of dementia directly to their relatives. Mrs. F stated that she does not want to tell the truth to her husband because it could cause his depression or aggravate the dementia.

"(After dementia signs are caught) I said "we should go see the doctor but I am going to see the doctor first". I said "I think he has started his dementia or something but I don't want to talk". We made an appointment and we went to up. She said "we can have some tablets" (Mrs. F).

Sometimes, older people with dementia find it hard to accept their problems. Mr. B denied his problems and did not understand why he should give up his driving licence.

“He is not able to drive, his licence have been taken away. He didn’t accept that he had a problem and he didn’t accept the fact that he was not safe driving” (Mrs. B).

Family carers also felt angry or depressed due to their relatives’ problems but they accepted and understood that the disease caused these problems. They blamed the dementia disease.

“It was very strange to me. Nobody in my family does have dementia. I was put out as time goes on for a long period. I am desperate and knocked out because of the illness not her. I sometimes shout and argue to her illness not Kat” (Mr. G).

“He has been changed. I know it is not his fault. He is much better if he would not develop this disease. We would have a different life” (Mrs. B).

Table 3-6 shows the situation regarding the use of dementia medicine in Scotland. Most patients took medication while only three people did not get medicine for dementia. All medicine users received free medicine, thus, their economic status did not affect their use of medicine. Non-users of dementia medicine consulted with their doctors. One of the non-users had experienced failings in dementia medicine and the rest of the non-users had vascular dementia.

Table 3- 6 Use status of dementia medicine in Scotland

	Carer	Older people with dementia	Kinds of Dementia	Dementia Level	Use of Medicine
HI	Mrs. A	Mother (75, F)	Alzheimer	Severe	Yes
	Mrs. B	Husband (79, M)	Alzheimer	Moderate	Yes
	Miss. C	Mother (82, F)	Vascular	Moderate	No (doctor decision)
	Mr. D	Father (85, M)	Alzheimer	Moderate	Yes
	Mr. E	Mother (77, F)	Alzheimer	Moderate	Yes
	Mrs. F	Husband (75, M)	Alzheimer	Moderate	Yes
	Mr. G	Wife (77, F)	Alzheimer	Moderate	Yes
	Mr. H	Wife (80, F)	Alzheimer	Severe	Yes
LI	Mr. I	Wife (78, F)	Alzheimer	Severe	Yes
	Mr. J	Wife (75, F)	Alzheimer	Moderate	Yes
	Mrs. K	Mother (79, F)	Alzheimer	Moderate	No (doctor decision)
	Mrs. L	Mother (83, F)	Alzheimer	Moderate	Yes
	Mrs. M	Mother (93, F)	Vascular	Moderate	No (doctor decision)
	Mrs. N	Mother (82, F)	Alzheimer	Moderate	Yes

The second of the most common dementias is vascular dementia which is associated with strokes caused by high blood pressure, diabetes and heart disease, etc. As a result, they need medicines for prevention or the reduction of further strokes, medication for blood pressure control, heart disease, diabetes use for vascular dementia treatment (Alzheimer Scotland, 2002:5). According to Mrs. M, they received high blood pressure medication but it was not particularly dementia drugs such as donepezi (Aricept) or galantamine (Reminy) which is used for Alzheimer's disease, although some studies recommended that these drugs might help vascular dementia (ibid, 5).

“No medication. Alzheimer dementia there is medication but vascular dementia there isn't medication” (Mrs. M).

Carers state that ‘drugs do help her slow it down’. Some carers found that the dementia medicine was effective for a while but they faced the time when the drugs did not work like before, as Mrs. F states:

“She went to memory clinic, she get medicine. The drug does help her slow it down” (Mr.G).

“She gave him tablets. It worked brilliant and it slowed it down completely. From last year, it didn’t work like that” (Mrs. F).

Whenever they decided to stop the medicine they consulted with a professional. Mrs. B discussed her husband’s drugs with her pharmacist daughter. Some carers felt the medicine did not affect their relatives’ dementia, thus, they consulted their psychiatry nurse and GP or doctor, etc.

“She takes Aricept whether that is good or not. We do have a psychiatry nurse comes and visits. He will be back in 3 months time because he was not very happy about previous test. This particular type of medicine does not have any use for her. It is just experiment stage” (Mr. J).

“After a wee while we did not know whether it was dementia. So we’ve got to see the GP. I wanted any medication suitable for her. So she did brain scan and had a vascular type of dementia. No medical treatment” (Miss C).

Carers in Scotland acknowledged the importance of dementia medicine, and thus pointed out that the accessibility of dementia medicine should be equal to all the older people with dementia. They

stated that medicine should be free and they felt it was right for older people with dementia.

“It is good help for you. Agitation. Medication is free. We are fortunate. ... I am very thankful of that. The medication should be free all the people, because we pay tax and insurance as well” (Mrs. B).

“Mum gets free Aricept. If she hadn’t got it she went down much, much quickly. I would feel very, very angry if she couldn’t get it. She got it early stage. I would feel strong about that. There is no doubt the state should pay for it” (Mr. E).

At present, sufferers related to the interviewees in this study received free dementia medicine. However, some of them experienced difficulty in getting free drugs in the past. For example, Mr. I had difficulty in obtaining dementia drugs in the beginning. According to Alzheimer Scotland (2009d), Donepezil¹⁶ became available in the UK in 1997 and sufferers in some areas did not receive it.

“I am sad that people who are elderly who have dementia have no experience of ability to fight and press right buttons. I had to fight for my wife to get Aricept. If I did not contact medical people and MP I might not get them.” (Mr. I).

Carers in Scotland had a diagnosis of dementia for their relatives and understood the behaviour problems owing to the dementia disease. Whenever they do have problems with medicine, they do not have any

¹⁶ Aricept, the brand name for the drug donepezil hydrochloride, was the first licensed dementia drug in the UK and launched in 1997 (Alzheimer Scotland, 2009).

reluctance to discuss it with a specialist in the health care system. Moreover, carers insisted on the significance of dementia medicine even if there is no cure for dementia. They even believed the medicine should be free for all older people with dementia. They were very active to get free dementia medicine. In fact, all Scottish older people with dementia in this study received free medicine. The carers, furthermore, had positive attitudes towards the use of medicine.

Treatment of Dementia in Korea: No Cure, Useless

Carers regret a late diagnosis of dementia for their relatives (Connell et al., 2004:505). Many Korean carers in this study regretted that they did not recognise the symptoms and delayed a diagnosis. Carers in Seoul and Suwon felt sorry that they did not recognise dementia symptoms early.

“In the past, people recognised dementia as ManRyeong which would naturally contract in old age. I wished I had recognised it in 1998. If so, the situation is better now” (Mr.B1).

“In a day, my mum lost her way and was in a police station. At that time, if I had tried to treat her disease, this symptom could not have been serious like this” (Mr. F2).

The diagnosis of dementia can be confusing news to carers. Some carers were very depressed after a diagnosis of dementia. In Suwon,

one spouse carer, Mrs. K2, had treatment for depression due to her husband's diagnosis of dementia.

“If my husband had a difficulty in legs or five viscera, I could have communicated with him. The dementia prohibits our conversation. At first I fell into a slump... I hope to travel with him in old age... I used to be in a state of depression at least for three months” (Mrs. K2).

However, some carers felt that a diagnosis of dementia helped them to be ‘more patient and understanding’ their relatives with dementia (Connell et al., 2004:505).

“If we know dementia is a disease, we will care for her very well. But we recognise it as her personality and dislike it. Before the diagnosis of dementia, we all were confused” (Mr.B1).

“In the first stage of the disease, my husband thought we must teach her strange behaviour. So there were conflicts between us. After the diagnosis, the conflicts disappeared” (Mrs. H1).

On the other hand, some carers in Seoul and Suwon were angry about behavioural problems, although they knew their relatives had dementia. Mrs. N2 and Mrs. L1's husbands had some conflicts with their relatives' behaviour and still doubted that it was caused by dementia. In fact, in both cases, neither had been educated or informed about the characteristics of dementia.

“It was not until the diagnosis of dementia that I know her situation. Eventually I understood her behaviour. But

her son, my husband, does not accept his mum's disease. Until now, he is cross with her" (Mrs. L1).

"Even until now, I ask my mum's carer whether or not she really has dementia or whether she is cross with me..." (Mrs. N2).

Carers stated that they did not feel shame about dementia. In Seoul and Suwon, carers stated that they did not have negative attitudes towards dementia itself, although they felt sorry for people with dementia.

"I take pity on a person with dementia rather than have a bad conscience on it" (Miss. N1).

"It is not a shameful thing to take dementia. Who knows anyone of us get diseased?" (Mr.D2).

However, some carers indirectly showed signs of a stigma attached to dementia. In particular, Mr.C1 wanted to commit suicide if he had dementia. Moreover, some carers feared that they will develop dementia like their relatives (Corner & Bond, 2004:147).

"I will commit suicide by briquette gas poisoning" (Mr.C1).

"Because of dementia, she does not recognise her children. To live long is not good in this condition. It's better that she dies when the weather is good" (Mrs. F1).

"I don't have shame of dementia disease itself. But I worry that I would have dementia like my mum" (Mrs. J2).

Some carers started to prepare not only for the future of an older people with dementia after diagnosis, but also for themselves. Carers in Seoul and Suwon were concerned about their future, as shown below:

“After my mum took diagnosis of dementia, I insured myself ageing dementia. I am afraid dementia will be contracted” (Mrs.L1).

“Soon after diagnosis of dementia, I applied to the benefit given to households in absolute poverty. It’s for care homes later” (Mrs. J2).

Most carers in this study did not inform their relatives that they had been diagnosed with dementia. One of reasons is that the news could worsen their relatives’ dementia condition. Moreover, most of them diagnosed dementia when they were already at a moderate stage and therefore the carers did not disclose the diagnosis to their relatives.

“My grandmother does not know her diagnosis of dementia. We don’t say it to her because we are afraid of getting worse when she knows it” (Mr.M1).

There were 18 people that used medicine whilst 10 people did not use medicine for dementia. There is no difference between Seoul and Suwon. The reason why the number of medicine user is not different can be explained by long-term care pilot scheme which does not effect on the medical treatment. In fact, long-term care pilot scheme covers care for older people with dementia, not diagnosis and medical

treatment of dementia. Therefore, the cost of diagnosis and medicine is not different between Seoul and Suwon. In the case of non-users of medicine, many of their decisions were made by carers without consultation with a professional.

Table 3- 7 Use status of dementia medicine in Korea

		Carer	Older person with dementia	Kinds of Dementia	Dementia Level	Use of Medicine
S E O U L	H I	Mrs. A1	Mother (82, F)	A 1)	Moderate	Yes
		Mr. B1	Wife (75, F)	A	Severe	No (doctor decision)
		Mr. C1	Mother (80, F)	V 2)	Moderate	Yes
		Mr. D1	Mother (86, F)	A	Moderate (bedridden)	No
		Mr. E1	Mother (78, F)	A	Moderate	Yes
		Mrs. F1	Mother (90, F)	A	Severe	Yes
		Mrs. G1	Father (91, M)	V	Severe (bedridden)	No (carer decision)
	L I	Mrs. H1	Mother (83, F)	A	Moderate	Yes
		Miss. I1	Mother (80, F)	V	Severe (bedridden)	No
		Mr. J1	Wife (75, F)	V	Moderate	Yes
		Mrs. K1	Aunt (90, F)	V	Moderate (bedridden)	Yes
		Mrs. L1	Mother in law (83, F)	A	Moderate	Yes
		Mr. M1	Grandmother (88, F)	A	Moderate	Yes
		Miss. N1	Mother (80, F)	A	Severe (bedridden)	No (carer decision)
S U W O N	H I	Mrs. A2	Husband (86, M)	A	Moderate	No (carer decision)
		Mrs. B2	Husband (77, M)	V	Moderate	No
		Mrs. C2	Father in law (89, M)	A	Severe	Yes
		Mr. D2	Mother (88, F)	A	Moderate	No (carer decision)
		Mrs. E2	Mother in law (80, F)	A	Severe	Yes
		Mr. F2	Mother (82, F)	V	Moderate	Yes
		Mrs. G2	Mother in law (78, F)	V	Moderate	Yes
	L I	Mr. H2	Aunt (79, F)	A	Severe	Yes
		Mrs. I2	Mother (88, F)	A	Severe	Yes
		Mrs. J2	Mother (76, F)	A	Moderate	Yes
		Mrs. K2	Husband (85, M)	ARD 3)	Moderate	Yes
		Mrs. L2	Mother (82, F)	A	Severe (bedridden)	No (carer decision)
		Mrs. M2	Mother (78, F)	V	Severe (bedridden)	No (carer decision)
		Mrs. N2	Mother (77, F)	V	Severe (bedridden)	Yes

Note: Kinds of Dementia, 1) A: Alzheimer 2) V: Vascular 3) ARD: Alcohol related dementia

Carers' attitudes towards medical treatment are significant in the use of medicine. Some carers heard that there was no cure for dementia and this led to reluctance to use medicine. However, dementia medication gives benefits for carers and older people with dementia by delaying development into the advanced stage of dementia and relieving symptoms. In this vein, some carers in Seoul and Suwon believe dementia medicine is effective.

"I changed drugs for dementia because there was little change of her condition at first. Ever since, the progress of symptoms has stopped. The progressive character also disappears" (Mr.C1).

"Since he takes the pills, his memory has been getting better" (Mrs. K2).

However, some carers in Seoul and Suwon did not feel that medicine was efficient because there was no cure for dementia.

"She has swallowed a pill but unfortunately... it didn't do the trick. In fact, the effect means her condition continues but getting worse little by little" (Mr.H2).

"My sister sent a good medicine for dementia from USA and my mum has taken it. But it is not getting better. I now know the medicine not cures her disease completely. It keeps current conditions" (Mrs.F1).

Moreover, carers disliked the use of medicine because they felt the medicines were useless for dementia.

"The hospital filled the prescription for dementia. However, the hospital told me this medicine didn't treat

the disease. So I threw it into a wastebasket and tried to do constant physical contact and praised her to the skies. Surprisingly, the condition has been improving gradually” (Mrs.M2).

“The medicine has not an impact on dementia despite taking for six months. Rather, the symptoms are getting worse. ... My mum hates to take the medicine because she thinks it’s a poisonous drug so it’s really hard to give her the medicine. Eventually taking the medicine is stopped” (Mrs.L2).

Miss N1’s mother suffered side effects from the medicine so she decided to stop the medicine without a doctor’s medical consultation.

“My mum had taken a medicine but now stops everything. Because the medicine makes a stomach trouble and I think it is not effective. I am reluctant to give any drug...” (Miss. N1).

A lack of knowledge regarding the treatment of dementia influenced carers to stop the medicine. However, carers that received a good explanation of medical treatment from a professional accepted using medicine.

“I have thought dementia could make early death. At first, I gave my husband some medicines for healing dementia. But there was little change so stopped to drug him. The doctor concerned phoned, “Why don’t you take the medicine?” I said, “I don’t give the medicine to my husband. If he has MangRyeong, it’s happier to die as soon as possible”. The doctor replied, “No, he never dies earlier than you because he is not under stress. The medicine is useful to keep his present condition” (Mrs. K2).

Mr. B1 stated that the doctor did not give his wife dementia drugs any more due to their ineffectiveness in treating serious dementia.

“A hospital doesn’t provide her with drugs for dementia. It said, the medicine might not be effective enough after dementia promoted to some degree” (Mr.B1).

All of carers in this study, apart from Mrs. H1 paid for dementia medicine even if they were under MA. Mrs. H1 worried about the dementia drugs fee for next year owing to stop supporting the free medicine from charity programme by KT&GC.

“I am worried about medicine because it’s free just for one year. So I don’t often give the drug to my mum. I would like to save the medicine. I have sought a way with a social worker. The social worker gave a promise to find the way” (Mrs. H1).

As can be seen in the above description, Korean carers had a greater regret for late diagnoses. However, they were relieved by a diagnosis for their relatives’ dementia because they understood the cause of their relatives’ behaviour problems. Some carers might have conflicts despite their relatives’ diagnosis of dementia due to a lack of information. There was a stigma attached to dementia, although many carers did not feel shame about dementia. However, carers now tend to understand dementia as a disease. The lack of knowledge or misunderstanding of dementia leads to a fear of dementia and a stigma towards dementia. The government, therefore, should provide information on dementia to change attitudes.

Regarding the use of medicine, a lack of knowledge about dementia medicine and the economic burden influences the reluctance to take medicine in Korea. First of all, 10 older people with dementia did not use medicine and 6 carers made a decision not to use medicine without consulting a specialist. Many Korean carers felt that dementia medicine wasn't useful because there is no cure for dementia. Secondly, Korean health care did not provide free anti-dementia medication, even for the people in a low-income bracket. Moreover, they believe there is no cure for dementia. Therefore, the carers think using medicine is waste of money.

3.5 Summary

The aim of this chapter was to give an insight into carers' perspectives on the diagnosis of dementia. This section aimed to sum up where the different attitudes between carers in Scotland and Korea arose.

The carers' attitudes can be summarised as follows. Firstly, Scottish carers felt the signs from dementia as 'something different or wrong', whilst Korean carers recognised the signs as 'any natural step presented in normal old age'. Scottish carers recognised the symptoms of dementia earlier than Korean carers. Regarding the recognition of dementia, previous studies show that Asian carers attached a strong

stigma to dementia because they felt shame about it, based on a cultural aspect; therefore, they hid it in their communities. This study found that there was only one case which mentioned a stigma about dementia, but the man got advice from a neighbour. Moreover, carers consulted with neighbours about signs of dementia. Therefore, the stigma is not based on a cultural aspect but a lack of knowledge.

Secondly, Scottish carers had an immediate medical consultation after the first signs of dementia, while Korean carers tended to delay a medical consultation due to the lack of knowledge of symptoms and the expense of the process of assessment.

Thirdly, Scottish carers expressed the significance of anti-dementia medicine. In contrast, Korean carers did not feel the importance of medicine because there is no cure for dementia. A lack of knowledge and the expense of anti-dementia medicine may cause this result in Korea. From the findings, it is clear that the crucial difference in the knowledge of dementia lies in the health system, whether or not the early diagnosis of dementia is equipped.

Scottish carers' and Korean carers' attitudes towards the recognition of dementia signs, diagnosis, and the treatment of dementia are different. These different attitudes are affected by social policy rather than culture. Firstly, if carers and older people with dementia have knowledge of dementia, it will lead to the early recognition of signs and a dementia diagnosis. Knowledge of dementia, thus, is a very important factor in early diagnosis.

Knowledge of dementia is based on the health policy; thus, policy campaigns are important to improve public knowledge on dementia.

Secondly, the different health care systems result in different attitudes towards dementia, diagnosis and treatment. Scotland has the NHS which is a universal free health service but Korea has the NHI and the MA which are very limited. Moreover, the Korean health system is not free, and even the MA for the low-income bracket requires payment for the treatment and diagnosis of dementia at present (2007). As a result, the health system may delay dementia diagnoses and treatment in Korea.

On the other hand, the Health, Welfare and Family Affairs Minister, Chun, JeaHee (2008) announced the General Plan for Dementia. It enforced the free diagnosis of dementia but does not cover an MRI or CT to search for a cause of dementia. It will encourage dementia diagnosis but still does not get rid of barriers to the accurate diagnosis of dementia. In 2008, the government announced a voucher for free medicine for those in the low-income bracket (MHWFA, 2008). Therefore, it may encourage active treatment for older people with dementia. Yet, the economic burden will still be a barrier to treatment through anti-dementia medicine, even among people who are over the poverty line.

Chapter 4. Family Care for Older People with Dementia in Scotland and Korea

Caring for older people with dementia can be very complex and stressful. Moreover, it may be more challenging than caring for an older person with physical disabilities because of the ‘unpredictable and progressive nature of the illness’ (Alzheimer Scotland, 2008: 5). Therefore, it imposes a high level of burden and stress on the carers. However, the older people want to be kept at home and their carers are in agreement with this. Family care is crucial when caring for older people with dementia at home. In other words, family care is the ‘mainstay’ of older people with dementia in community care (ibid.). In fact, the majority of care given to older people with dementia is provided by family members. Most family carers are generally female - a wife, daughter or daughter-in-law (Knapp et al. 2007: 16). Some studies argue that informal care¹⁷ means that older people can continue to live in their own home (Green, 1988; Parker, 1990; Allen et. al. 1992: 10). In addition, family care, which is unpaid care, is an important element to consider in terms of the cost of long-term care, and therefore, many advanced countries have established support for this kind of caring (Knapp et al. 2007: 16-17).

¹⁷ Twigg (1992) defined informal care provided by family or marital relations as unpaid, based on the motivation of love, obligation and duty (Kirk & Glendinning, 1998: 371). In this study, informal care means family care.

This chapter examines a number of family care features in Scotland and Korea under different cultural and social welfare conditions. Previous studies have focused on the cultural aspect of family care. Scotland and Korea have different cultures and social policies for older people with dementia. For example, Scotland is a Western society, which is subject to individualism, while Korea is an East Asian society with familialism. Moreover, there is a social policy difference in supporting older people with dementia and carers between Scotland and Korea. For example, older people with dementia and their carers receive a pension or social allowance in Scotland, whilst in Korea they rarely have these benefits. Therefore, this chapter aims to investigate how culture and social policy affect family care.

It focuses on who the carers are, where the older people live, what kinds of care the carers provide, which other family members are involved in the care, what has changed in the carers' lives since becoming a carer, the level of burden and stress involved in being a carer, and the motivation for providing care to their relatives with dementia.

4.1 Family Care for Older People with Dementia in Scotland

Identification

According to Alzheimer Scotland, 60 per cent of people with dementia live in the community and 40 per cent live in care homes and hospitals. Further, it estimates that between 34,767 and 39,017 people with dementia live in the community, whilst between 23,178 and 26,012 people with dementia live in care homes (Alzheimer Scotland, 2007: 18-19). There is no exact number of carers for people with dementia available, but the 2001 Census found that there were 481,579 informal carers for all physical or mental disabilities in Scotland, of which 305,610 provided 1-19 hours per week, 60,294 provided 20-49 hours and 115,675 provided 50 or more hours per week (ibid.: 23).

In Scotland, 70 per cent of people with dementia in the community live with their carers, who are usually their spouse or daughter (Alzheimer Scotland, 2009a). According to Table 4-1, which shows the interviews conducted for this study, the majority of carers are adult children, for example there were six daughters and two sons interviewed in this study; however, there were also six spouse carers,

in particular, two wives and four husbands. In fact, in this sample, the prevalence of dementia is higher among females, as there are more male spouse carers than female spouse carers. On the other hand, according to this study, family care in Scotland is dominated by female carers.

Most carers are over 40 years old. The age of adult children of older people with dementia is between 42 and 59, and spouse carers are generally aged between 71 and 83. Most of the adult children are married, except Mr. D and Miss. C. Five out of eight of the adult children carers have a full- or part-time job. Two of the adult children carers, Mr. D and Mrs. K, are unemployed. In the case of spouse carers, all were retired.

Table 4- 1 Carers and the living arrangements in Scotland

	Carer		Carer's Marital status	Carer's Employment status	Living with or apart from care recipient
H I	Mrs. A	Daughter (50)	Married	Full-time	With (moved into mother's house 7 years ago)
	Mrs. B	Wife (71)	Married	No	With
	Miss. C	Daughter (46)	Single	Full-time	Apart (10 days work and 4 days stay in mother's home)
	Mr. D	Son (58)	Single	No	With (moved into father's house 2 years ago)
	Mr. E	Son (42)	Married	Full-time	Apart (within 10 minutes by car)
	Mrs. F	Wife (73)	Married	No	With
	Mr. G	Husband (73)	Married	No	With
	Mr. H	Husband (83)	Married	No	With
L I	Mr. I	Husband (75)	Married	No	With
	Mr. J	Husband (78)	Married	No	With
	Mrs. K	Daughter (43)	Married	No	Apart (within 2 minutes on foot across street)
	Mrs. L	Daughter (45)	Married	Full-time	Apart (within 30 minutes by car)
	Mrs. M	Daughter (58)	Married	Full-time	Apart (within 5 minutes by car)
	Mrs. N	Daughter (59)	Married	Part-time	Apart (within 5 minutes on foot)

Living arrangements

Six of the older people with dementia in the table above do not live with their carers. All of them live alone, except Miss. C's mother who lives with Miss. C's younger sister. Carers who live with older people with dementia are usually their spouse. Only two of the adult children carers live with their parent with dementia. Accordingly, the adult children of older people with dementia tend to live apart. Although most adult children live apart from their recipient, most of them live at a very close distance.

According to Table 4-1, eight of the fourteen carers live with their relatives. Mr. D and Mrs. A moved into their parents' house in

order to provide care. They decided to move into their parents' home rather than bring their parents into their own home, because dementia can be worse when the person's environment is changed.

"I have my own house in M-burgh. I knew when I visited him that he needed more help. One weekend, I came up. I could see he just wasn't coping, you know. So I decided to... It was a very big decision for me because it changes your whole life, your whole career" (Mr. D).

"This is mum's house. I have my own house. We made this decision because her dementia is easier to deal with if her environment is kept the same. So we decided to move in here and look after her" (Mrs. A).

However, six out of eight adult children live apart from their parents with dementia. Although most carers provide regular care for their parents, they seemed to feel reluctant to live with them, especially those carers who were married. Here are some reasons for them living separately from their parents:

"My grandmother actually had to live with us when we were young for a while. My sister had to give up her bedroom for her... I remember that being quite a difficult situation for the family ... Currently, there is no problem with her coming to stay with us for few days. No problem at all. ... I certainly wouldn't look at it (live together) as long-term solution" (Mr. E).

"It is too much to live with dementia all the time, but it is ok when I leave my mum's house as I can switch off. I am still cooking her meals and doing things for her, and do her shopping" (Mrs. K).

They were likely to keep their own (nuclear) family life separate from caring for their parents. Moreover, they worried that it could cause conflict with their children and partner, and might therefore result in more of a burden if they were all living together.

On the other hand, one carer brought her mother nearer to her house rather than living in the same house. Mrs. N's mother used to live in an upper-floor flat and so she was worried about her falling down the stairs. Her mother moved to a ground-floor flat, where access was easier. Moreover, she can now provide care more easily due to the flat being closer.

“We just bought a new house for her. We had to move her about a month ago. It's been quite difficult but she's settled in quite well. (Does she live near here?) Just about five minutes round that corner. It's nice. Ground floor, whereas before she was on the upper floor” (Mrs. N).

This study shows that more than half of the family carers live with their relatives with dementia, but these are mainly spouses. In the case of adult children carers, most live apart from their relatives but within a close proximity. Two of the adult carers have moved into their parents' house since the diagnosis of dementia.

Family Care: Practical Care, Financial Care and Cognitive Care

Family carers, whether living together or apart, are a crucial factor in people with dementia being able to remain living at home (Parsons, 2001: 123), and provide many kinds of help for their relatives. Allen et al. (1992) divided the care into 'functional' and 'personal'. 'Functional' care includes shopping, cleaning, cooking, laundry, transport and so on, whilst 'personal' care includes dressing, washing and getting into bed, etc. Moreover, caring for someone with dementia requires more participation, decision-making and emotional support because of the deteriorating nature of the condition. In addition, caring for older people with dementia is costly, as there may be fees for medicine, continence problems and private care fees, etc. This category of help can be divided into 'practical care' such as functional and personal care, 'financial care' such as informal income support, and 'cognitive care' such as decision-making and emotional support.

Most carers, especially those who live with their relative who has dementia, provide practical care, in particular, cleaning, cooking, shopping and assisting with showering, etc.

"Basically, I have to do everything in the house - cooking, washing, shopping and looking after her. I have to shower her as well, and I have to prepare all the food. I do more or less everything" (Mr.I).

"I do all the housework myself. He can't do anything in the house now. You have to more or less dress him. ... He wouldn't wash his hair. He wouldn't bathe himself. He doesn't shower." (Mrs. F).

Moreover, carers and recipients who live at the same house are together almost all of the time, except when using formal care services¹⁸ or receiving help from other informal carers. Mrs. B commented that her husband is like her shadow.

“I cannot leave him in the house on his own, and I cannot let him go out on his own. We have to be together all the time. (How do you cope with the shopping?) He comes with me. Have you heard the expression ‘me and my shadow’? He’s like my shadow” (Mrs. B).

On the other hand, some carers provide care from the outside, and visit or contact their relatives on a regular basis. Although they live separately, they provide practical help just like co-resident carers. Carers who live apart from their relative with dementia provide a wide range of care, and some visit the relative everyday, and provide meals and personal care.

“She lives two streets away. ... Usually, I go up at about half past nine and get her up and dressed, make her breakfast, do any washing and tidy up. I leave her for a while and go back at half past 12. I make her some lunch. I cook her meals, put them all in a plastic tray and put them in the freezer. On Wednesdays, my husband and I go shopping for her” (Mrs. K).

Moreover, they not only provide practical care but also emotional support. One carer said that whenever he calls his mother he checks if she is alright and how she is feeling.

¹⁸ Free personal services, day care, meals on wheel and respite care etc are available for older people with dementia in Scotland (Further discussion will be developed in the chapter 5).

“We’re always trying to see her, probably once a week with the kids. It’s mostly habit for me. ... I phone her every night to tell her to take her pills, just to make sure she does. At the weekend, either my sister takes her or she is here overnight. ... I know she doesn’t feel great, but I can pop over at lunchtime or whenever” (Mr. E).

Miss. C provides functional and personal care to her mother when she stays with her.

“My sister lives with my mum, but I work ten days (in the Highland) and I come down on my four days off, and so I come down every fortnight for those four days. It gives my sister a break. Now, my mum is not capable of washing or dressing herself. When I am here, I cook all the meals and do other things” (Miss. C).

As mentioned above, some married adult children carers of older people with dementia feel they have to balance caring for their children and caring for their parents.

“She lives alone. (How far from your house?) About 5 minutes by car. Once a week she usually comes to me for dinner on Sunday night. I pop up once or twice during the week, just for a short time. Sometimes, you feel torn. I feel my mum should come round on a Sunday, but my daughter wants to do something else on a Sunday. You’ve got to ... it’s always a balancing act” (Mrs. M).

In terms of financial support, there was no mention of regular financial support among the carers. However, five of the older people with dementia live in houses that belong to their adult children, rent free, although three carers have inherited their parents’ house. This

has meant that few older people with dementia receive financial support from their adult children. Apart from being able to live rent free, older people with dementia have not received any regular financial support from their family.

Nevertheless, the older people with dementia receive their attendance allowance, basic pension and pension credit¹⁹. Since the Beveridge Report, retired people have had financial security through the pension and benefit system²⁰. Since the Beveridge Report, most

¹⁹ Benefits and Services for Elderly People with Dementia in Scotland

Category	Type	Benefit
Income security	Means-tested	- Pension credit - Cold weather payment - Housing Benefit and Council Tax Benefit
	Contributory	- Basic retirement pension (contributory) - Earnings-related retirement pension
	Demogrant	- Basic retirement pension (non-contributory) - Attendance allowance - Carer's allowance - Winter fuel payments - Concessionary television licences - Christmas bonus

Source: O'Dea et al (2007), A Survey of the UK Benefit System, The Institute for Fiscal Studies, <http://eprints.ucl.ac.uk/14953/1/14953.pdf>

²⁰ In the case of social assistance, there is pension credit, housing benefit, council tax benefit and social funds available. Generally, people of pension age receive pensions and pension credit if they are below the poverty line. Elderly people with dementia can receive more benefits, such as attendance allowance, due to their illness, winter fuel payments and a Christmas bonus. The Carer's Allowance is provided for carers who are not able to work because of caring for their relatives with dementia. Accordingly, there are various state benefits available for elderly people with dementia. Table 5 shows these benefits and their costs in 2008.

Benefits and Pension Rates, 2008

Division	Benefit and Pension	Weekly
Social Assistance	Pension Credit*	Guarantee Credit: Single £124.05, Couple £189.35 Savings Credit: Single £19.71, Couple £26.13
	Social Fund (Cold Weather Payment)	£8.50
	Housing Benefit***	Rent fee

older people have received at least one of the Department of Work and Pension (hereafter DWP) benefits. For instance, 99 per cent of people over the state pension age who are resident in Great Britain have claimed at least one government benefit (DWP, 2003). Of all the state benefits, state pension is the largest and most common income source.

	Council Tax Benefit	Rebate for second adults on Pension Credit: 25% Second adult's gross weekly income is less than £169: 15% Second adult's gross weekly income is between £169 and £219.99: 7.5%
Pension	Basic State Pension (contributory)	£90.70
	Basic State Pension (non-contributory)	Over 80 –£54.35
	Based on your husband's NIC	£54.35
	Earnings-related State Pension	Maximum £148.14
Others	Attendance allowance	Higher rate £67, Lower rate £44.85
	Carer's allowance	£50.55
	Winter fuel payments (only once)	Aged 60-79: £250 or £125 (shared payment) each Aged 80 or over: £400 or £200 (shared payment) each
	Concessionary television licences	Free for 75 or over
	Christmas bonus**** (only once)	£10

Note: * for each £500 or part of £500, of capital (saving and investments, etc.) you have above £6,000, your entitlement is reduced by £1 a week. If you live in a care home, your entitlement reduces for each £500 or part of £500 of capital you have above £10,000.

** Any period of seven days when the temperature is freezing or below.

*** You can't get housing benefit: have savings of over £16,000, unless you are aged 60 or over and getting the 'guarantee credit' of Pension Credit; you live in the home of a close relative.

**** To get a Christmas Bonus you must be entitled to at least one of the following benefits: Attendance Allowance, Constant Attendance Allowance, Contribution-based Employment and Support Allowance, Disability Living Allowance, Incapacity Benefit at the long-term rate, Industrial Death Benefit, Carer's Allowance, Mobility Supplement, Pension Credit – the guarantee element, State Pension (including Graduated Pension), Severe Disablement Allowance, Unemployability Supplement or Allowance, War Disablement Pension if aged 65 or over, War Widow's Pension, Widow's Pension, Widowed Mother's Allowance, Widowed Parent's Allowance.

Source: DWP, 2008, Benefit and Pension Rates,

http://www.jobcentreplus.gov.uk/JCP/stellent/groups/jcp/documents/websitecontent/dev_015666.pdf

In 2006/2007, 95 per cent of pensioners received a state pension, 72 per cent received investment income and 59 per cent received income from an occupational pension. All other available sources were received by less than half of all pensioners, including earnings, which were received by only 16 per cent (DWP, 2008b: 31). In terms of pensioners' income, state benefits made up 44 per cent, occupational pensions 25 per cent, investment income 10 per cent and personal pensions just 3 per cent (ibid.). Accordingly, most of the interviewees said that they have just enough income to maintain their current standard of living.

"She worked in a bank and had a good position. I worked as a policeman. Therefore, we managed our finances and we receive a pension and occupational pension. We don't have any financial problems" (Mr. G).

"My wife receives a retirement pension, pension credit and attendance allowance. This house is owned by my daughter, so we don't need to pay any rent. It is enough for us" (Mr. H).

They recognise this benefit as a reward for their hard work. Therefore, they think it is their right to claim the benefits.

"I am going to be 60 soon. I have got two or three private pensions and a national pension. I will also get a free bus pass. It's great. There are a lot of people who are unable to pay their bus fare. It is brilliant idea. It is my right because I pay tax" (Mrs. N).

"I have paid tax all my life and still pay it now. We expect the government to help when we encounter bad times. We have paid tax all our life and saved money for

a rainy day. We are both retired. We have a good standard of living. The government also helps us with an attendance allowance and a pension” (Mr. G).

Although most people receive a state pension, there are still people living in poverty. Richard Titmuss (1955) mentioned that in Britain, there are ‘two nations in old age’: one benefits from occupational pensions and private savings, and the second depends entirely on basic state pensions and means-tested assistance (Falkingham, 1998: 108). Until today, Titmuss’ argument has been applicable in the UK. Although most older people receive a basic state pension, some still live in poverty. There are 11 per cent (before housing costs) or 7 per cent (after housing costs) of pensioners who live in absolute poverty, which means ‘individuals living in households whose incomes are below 60 per cent of inflation adjusted median income in 1998/99’, while 20 per cent (before housing costs) or 15 per cent (after housing costs) live in relative poverty, which means ‘individuals living in households whose incomes are below 60 per cent of median income in the same year’ in Scotland (The Scottish Government, 2007). It has been reported that 32 per cent of pensioners received at least one income-related benefit, for example Pension Credit, Housing Benefit or Council Tax Benefit, in 2006/2007 (DWP, 2008b: 8). In Scotland, 25.5 per cent of people aged 60 or over receive an average of £40.99 per week in pension credit. This particularly helps persons who have a state pension but have no occupational pension because the level of

state pension is very low. Some of the interviewees insisted that the state pension should be increased.

“We both receive a pension. He has a state pension and a work pension. It totals a thousand pounds a month. A lot of people do not have a work pension. State pension is too small. It should rise” (Mrs. F).

Pensions are a blind spot, especially for women who work in a family business. The basic state pension is available to all, whilst earning-related pensions are not.

“I receive a state pension and have savings. I used to work in my husband’s office but I did not get paid. Therefore, I am not entitled to a second pension. We have a married couple’s pension. It is not fair” (Mrs. B).

In the case of carer’s allowance, the interviewees think that this is too small and argue that the coverage of this benefit should be extended.

“You don’t get carer allowance but you can get attendance allowance. It is wrong. It is much harder to care for someone else when you are over 65” (Mrs. F).

“I get a carer allowance of £178 a month. I don’t have a full-time job because I am a carer, and although I could work two days a week and still receive a carer allowance, it’s not enough to live on. I am lucky that my husband has a good income and our children are grown-up” (Mrs. K).

Older people with dementia can be entitled to various benefits and compensation. However, the information on how to receive this is not easily accessible:

“Nobody tells you what you are entitled to unless you ask. For example, I phoned up to ask about Pension Credit and talked to them for 20 minutes. Now we receive £500 a month” (Mrs. N).

Accordingly, all older people with dementia in this study receive at least a state pension or pension credit. Therefore, they are financially independent from the family. In fact, the average weekly gross income in Scotland is £481 and £233 respectively²¹.

In Scotland, there is Power of Attorney according to the Adults with Incapacity (Scotland) Act 2000²². It is ‘an authority given by an individual (known as the Granter) to another person(s) (known as the Attorney/s) to deal with aspects of the Granter's affairs (Public Guardian Scotland, 2009)’. There are two kinds of Power of Attorney: continuing (financial) Power of Attorney, which looks after the money

21 The average income of pensioners by region					£ per week			
Region	Pensioner couples				Single pensioners			
	Gross income	Benefit income	Net income BHC*	Net income AHC**	Gross income	Benefit income	Net income BHC*	Net income AHC**
Scotland	481	182	398	373	233	153	207	179
United Kingdom	504	178	409	384	244	147	211	182

Notes: (1) Data based on an average of three years of results from 2004-05, 2005-06, 2006-07 FRS data and updated to 2006/7 prices, *Before housing costs (BHC), **After housing costs (AHC)

Source: DWP, 2008b, The Pensioners' Incomes Series 2006-07, p. 28.

²² ‘The law in Scotland relating to people with dementia and other adults who have difficulty understanding and making decisions was almost completely changed by the ‘Adults with Incapacity (Scotland) Act 2000’ (Alzheimer Scotland, 2009b).

and property of an older person with dementia, and welfare Power of Attorney, which decides an older person's welfare such as decision about medical intervention and care (Alzheimer Scotland, 2009b). These Powers of Attorney can give for one person or more than one person as joint attorneys. Power of Attorney is a crucial factor for older people with dementia in terms of their well-being and happiness.

According to this study, most of the carers have Power of Attorney. Mr. E has responsibility of his mother's finances and well-being because he has Power of Attorney for his mother.

"When she started going downhill, which was long time ago now, I started looking after her finances. I have Power of Attorney. I deal with all the bills and her bank account. ... I collect her prescriptions, things like that. She was missing doctor's appointments so I started to take the responsibility for that as well." (Mr. E).

"My brother and I both have Power of Attorney so that we can decide what happens with the money. My mother gave us Power of Attorney after she was diagnosed. The lawyer said that she was ok to sign the Power of Attorney as she understood what it was" (Mrs. L).

Mr. D struggled with his sister because she wanted her father to go into a care home rather than stay at home. He wanted to get Power of Attorney so he could keep his father at home. Therefore, he was in the process of obtaining Power of Attorney through the court, but his father seemed to find it difficult to make decisions. In his case, his father received his diagnosis of dementia in the early stages according to his interview, but his father did not prepare for his future plan by himself.

“Their (doctor and social worker) plan is to offer welfare guardianship, because of the bad circumstances. My sister and I don’t get on and there have been a lot of problems. I had to go to lawyers who specialise only in dementia cases, and they are now handling this case for me. This is part of the reason why my lawyer felt that a guardianship would be the best scenario” (Mr. D).

It is uncertain whether all carers are given the Power of Attorney by older people with dementia in this study. However, it is clear that the legal system helps older people with dementia to retain their dignity and well-being.

This study demonstrates that Scottish carers provide practical, financial and cognitive care in various ways. However, family financial care is not needed compared to other forms of care in Scotland because older people with dementia have their own incomes.

Family Network

Family carers are supported by other family members who provide practical and cognitive care, and financial assistance. According to my sample, twelve out of fourteen carers in Scotland experience the involvement of other family members. Seven out of twelve carers who receive help from other family members, receive this on a regular basis. The carers who are spouses of older people with dementia receive a lot of support from their adult children. Other family

members not only provide care for older people with dementia but also respite for the carers.

Mrs. F and Mrs. B receive regular support from their son and daughter-in-law, even though they have hobbies and a social life at the time.

“My son and daughter-in-law live in Edinburgh, but on a Tuesday, they come down and look after him while my sister and I go to bingo. Once a month I go on a girls’ night out. Wednesday we go to D(son)’s for dinner. F(son) comes for dinner on a Saturday night. If I have something I really need to do I would arrange it with them” (Mrs. F).

“My daughter (not in Edinburgh) phones a lot. My son lives closer to me, and my daughter-in-law is very supportive. In winter, I go to a Scottish country-dance class on a Monday nights. I take my husband to stay with them. ... When I go to the carer’s meeting, which is one morning every month, she (daughter-in-law) comes to take my husband out for coffee” (Mrs. B).

Male spouse carers seem to receive more domestic support from their adult children than female spouse carers. In other words, they are not used to doing domestic work, and for that reason, their other family members provide help in this area, such as cleaning.

“My daughter will come to help us out on a Monday. Recently, she helped us tidy up the mess the painters left behind. We could manage on our own though” (Mr. J).

“Both my daughters work, but one of them comes up for an hour on a Tuesday and the other on a Thursday. ... She (daughter) comes up on a Saturday for two hours, and my other daughter comes up on a Monday. ... Once

*a month, my daughter comes to clean the whole house”
(Mr. H).*

Mr. E shares his caring role with his sister. They look after their mother at the weekend when she doesn’t receive any formal care services.

“I go every Wednesday evening. My sister normally takes her on a Friday evening and brings her back around Saturday lunchtime, or I would pick her up Sunday afternoon and bring her here to have tea on Sunday. My sister and I both live in Edinburgh, so between us we handle all the care. When my mother had a fall, my younger brother actually took her to stay with them for a couple of weeks when she came out of hospital, which was great!” (Mr. E).

Respite is very important for carers. Around five out of fourteen carers receive help from other family members whilst they are on holiday.

“My son (only son) is very good. He used to care for my wife when I was on holiday. He is coming up again in September when I am having another break” (Mr. G).

“My younger brother Je is very, very good. He comes whenever I ask him to. He used to take mum out.” (Mrs. A).

However, some of the carers do not receive support from other family members such as brothers and sisters. This has caused conflict among the family. Mrs. N and Mr. D did not receive any help from their sisters and brothers because of the conflicts in their relationship.

“I have a brother who is not very hands-on. I haven’t seen him for about 20 years as we fell out. He is an alcoholic, and my mother and I just couldn’t cope. Also my mum and dad got divorced a very, very long time ago” (Mrs. N).

“My sister doesn’t want to know. ... She couldn’t cope very well. She said, ‘I’ve got my career, I’ve got my pension to think of’. He (father) gave us most wonderful lives. I said, ‘I can’t believe it’. So we had a big falling out about this. She wouldn’t contribute at all or help with anything. Nothing” (Mr. D).

Based on my sample, Scottish carers receive regular participation from other members of the family, and therefore, it seems that the Scottish family network is strong.

Burdens of Carers

Caring for people with dementia is a very complex task and has an effect on the carers’ social life, mental health and physical health. The burden of caring increases due to the symptoms of dementia. The complexities of the illness result in high levels of stress (Alzheimer Scotland, 2007: 23). There are various symptoms linked to dementia that affect memory, understanding, judgement, personality, etc. Carers face the difficulty of dealing with their relatives’ dementia. They suffer sleepless nights, annoying repetition, etc.

“There are so many symptoms. You can’t have a proper conversation. They are obsessed with toilets or other silly things. He keeps taking his wallet out about 15 times a day. He puts things under his mattress. It is an

obsessive sort of behaviour. It is obviously just part of his illness (most bothering symptoms) (hmm..) Reputation can makes me a wee bit angry. You can't help it, but you just get on with it" (Mrs. F).

"My father sleeps about for about 3 hours per day. The evenings and overnight are the worst times. He goes to bed at maybe 10 or 11 o'clock, sleeps for about an hour or two, and then after that he's up all night. They have good days and bad days, so you get very little sleep – I have to sleep when he sleeps or I can't sleep at all" (Mr. D).

Three of the carers gave up their job in order to look after their relative with dementia, as they believed that they could not leave their relatives on their own. Moreover, Mr. D pointed out that his decision to give up his job resulted in turning his 'life upside down'.

"I was a hairdresser. I had to give that up to look after my mum. I used to work two days a week when my dad was still alive, so it was only part time. Becoming a full-time carer was a gradual process." (Mrs. K).

"I gave up my job to look after my father two years ago this month. ... He started needing care 24-7 about 3 years ago and it is very hard work. I thought it would be very hard work, but I didn't realise how frustrating it could be or how lonely. My life has turned upside down. Basically, I live his life ... for him. But I don't have any illness, thank goodness" (Mr. D).

Carers also gave up their hobbies or what they were interested in. Mr.

G gave up painting and researching his family tree.

Carers could be low in mood because of a decreased social network (Robinson et al. 2005: 345). Keeping a social network and social life helps carers to continue caring for their relatives. However,

most carers experience a shrinking of their social life. Mr. G experienced a lack of social life and gave up his personal hobbies because of his wife's dementia.

"My husband and I have a caravan. We don't let her use it any more because she is doubly incontinent and it is difficult to clean everything. I only use the caravan now when she goes into respite. I don't socialise as much as I used to." (Mrs. A).

"I would say that my social life is just about non-existent. We have some close friends that we have known since 1959. We go for a meal every month. Other than that ... I wouldn't paint for two years, but it's not her fault. She comes up every quarter of an hour, saying, 'I am lonely, do you want to come for tea?' ... So I just gave up. I gave up my painting and researching my family tree" (Mr. G).

One carer showed a strong will to care for her mother, but it made her reluctant to go on holiday or anywhere else. She wants to stay with her mother while she is alive.

"I haven't taken any holiday for a number of years. I just feel that our time is limited. I've got plenty of time to do other things later. She needs attention now, and I'm happy to give it. ... If I had 2 weeks holiday, I would find it hard to go away somewhere else and not see my mum for 2 weeks. I'd rather spend 2 weeks with her while she is still here" (Miss. C).

The case below shows the importance of other family members' encouragement in ensuring a carer maintains a social life.

"My social life is affected by Mum. ... It is not the same. That part of my life has changed. There was a time when

I just didn't go to town, but I like shopping, I just couldn't be bother to go. My husband said, 'You know you have to take a step back'. Now I do step back a bit" (Mrs. N).

Carers often face high levels of stress because of the difficulties of being a carer the lack of social life. Mrs. F stated that she got stressed because of her husband's dementia, and couldn't stop feeling like that.

"I'm afraid that I am a smoker. I keep saying I'll stop but it is not easy now. With my husband (woo...), I am stressed all the time. I go through there and have a cigarette, and I am fine after that. But how can you be angry with them? He doesn't realise. You can't get angry, as it's not their fault. I catch up with friends by telephone" (Mrs. F).

However, some carers solve their stress problems in different ways. For example, Mrs. B did this by using her computer. Moreover, many carers carry out activities like those mentioned above, such as dancing, bingo and girls nights out, which help to relieve their stress.

"(If you get stressed, what do you do?) I go on the computer, on the Internet. If we are in the house, I will go on the computer to look at photographs and things" (Mrs. B).

Scottish carers become distressed because of the problematic behaviour of older people with dementia, the lack of social services and the difficulties of being a carer. Moreover, they have packed in their job or stopped pursuing their hobby in order to provide the care. It is reported that some carers have been hesitant about taking a break

or spending time on their own. In this situation, support from other family members was found to be significant.

Motivation

Motivation for caring can vary due to cultural differences. Research has illustrated that daughters generally felt more obligation to care for their parents, whereas wives cared for their husbands because of their willingness to do so (Cahill, 1999; Gilliard, 2001: 85). On examining Scottish carers' motivation for caring for older people with dementia, there were very mixed responses. Most spouse carers stated that 'love' was the reason for them providing care.

"Because I love him. We have been married for 41 years. I got a special badge for the marriage. Ruby wedding. Nowadays, marriages do not tend to last very long. We are lucky" (Mrs. F).

"I look after her because I love her" (Mr. I).

Moreover, they mentioned that affection and religious beliefs affected their motivation to continue their caring role.

"We first got to know each other in Christian fellowship. She was my 27th birthday present. Motivation comes from what you believe in. Regardless of what people say, you have no greater motivation. You share your belief" (Mr. J).

There are many reasons for motivation to care for others. Mrs. B said 'love' and 'Christian belief' are her motivations for caring for her husband.

"I am a Christian and I have a strong faith. I believe very strongly in the vows we made to promise to look after each other in sickness and in health. ... I wouldn't necessarily say it is an obligation but something you want to do. I like it. It is something I want to do. I love him and he is my husband, even though he has changed" (Mrs. B).

George and Gwyther (1986) point out that spouses maintain their care-giving role because the recipients play a 'central role in their life' (Markle-Reid & Browne 2001: 280). Mr. H demonstrated that his wife was still the centre of his life, even though she has severe dementia.

"I don't have many friends here. I came from Glasgow. She and I stuck together. ... Some people do, some people don't. But I look after her. You marry for life. I take care of her. It is my duty. When you marry it is for better or worse. We've been married for 55 years" (Mr. H).

In the case of adult children carers of older people with dementia, they decided to be carers because of love and repayment. They seemed to feel more obligation to care for their parents with dementia. Around five out of eight adult children carers said that their motivation for caring was repayment and obligation.

"My own dad was an alcoholic. He didn't like me but my mum was always there to protect me. Now I am

protecting her. I just feel that she looked after me, so I will do the same for her. ... I was a mummy's girl. It is my choice, but not a duty:" (Mrs. A).

"Probably just because she looked after me. It's sort of roles reversed, isn't it? I am an adult now, she is a child now. I look after her and try to do what's best for her" (Mrs. L).

Three out of eight adult children carers stated that 'love' is their motivation for caring for their parents with dementia.

"Because I love my father. I can't change how I feel. I didn't have to do it. It was a big decision at the time, you know" (Mr.D).

"I am an only child. I've got everything. (Motivation for caring?) To keep her safe and keep her happy. (Why?) Because I love her, she is my mum. There is some obligation but it's something you want to do. You couldn't leave her, you couldn't neglect her" (Mrs. M).

Most Scottish spouse carers in this study showed that their motivation is based on love, whilst most adult children carers felt an obligation, repayment or responsibility. However, this study showed there was no clear boundary between love and obligation; in fact, most carers had mixed reasons for their motivation for caring for their parents with dementia, such as obligation, repayment, responsibility and love.

4.2 Family Care for Older People with Dementia in Korea

Identification of Carers

In Korea, family care, especially provided by adult children, for older people who are mentally or physically impaired and who live at home, is common (Chee & Levkoff, 2001). According to the Korea Institute for Health and Social Affairs, 43.5 per cent of people aged 65 and older lived with their children in 2004 (Jeung et al., 2005: 26). However, the multi-generational family dramatically decreased due to industrialisation and the increase in women's participation in the workforce (Lee, 2008: 707).

There is no general consensus for carers for older people with dementia, and therefore, it is difficult to identify the exact number of carers and who they are. However, Byun (1997) estimated that there were 218,096 older people with dementia and 982,432 carers. According to Jeung and others (2005), older people who need care, receive it from their spouse (36.1%) or son and daughter-in-law (40.6%), but in particular, the eldest son and daughter-in-law (28.6%). Daughters-in-law are the major carers in Korea due to traditional expectations, whilst daughters play a crucial role in the care of older people in Western countries (Kim, 2001: 401).

In the case of my sample of Korean carers, around twenty of these were adult children of older people with dementia, specifically eleven daughters, five sons and four daughters-in-law. Five of the interviewees were sons but the primary carers were their wives (daughters-in-law). Consequently, it could be analysed that there were nine daughters-in-law who had the role of carer. Five carers were spouses of the older people with dementia, whilst three were other relatives of the older people with dementia such as a niece, grandson or nephew. There is no significant difference between carers in Seoul and Suwon. This study shows that Korean carers are dominated by females.

Daughters were the major carers in the lower income group, whilst sons and daughters-in-law were the major carers in the higher income group. This can be explained by the income security system. In Korea, sons typically have an obligation to look after their parents. This tradition applies in the social security system. For example, the means-test of income support recipients includes the adult children's income, if the recipient has children, but the assessment of adult children's income is different depending on whether they are sons or daughters. The system treats daughters' income as less significant than sons' income. Therefore, there seem to be more daughter carers in the lower income group.

The majority of carers are aged over 60, with only two of the carers less than 40. The age of adult children of older people with

dementia is between 39 and 68, and spouse carers between 72 and 80. Most of the adult children are married, whilst five are widows/widowers or single. Eleven out of twenty-eight of the carers, except spouse carers, are employed in a full- or part-time job. More carers in the lower income group have an occupation than those in the higher income group.

Table 4- 2 Carers and the living arrangements in Korea

City		Carer		Carer's Marital status	Carer's Employment status	Living with or apart from care recipient
Seoul	H I	Mrs. A1	Daughter (52)	Married	No	With (moved into daughter's house in 2005)
		Mr. B1	Husband (77)	Married	No	With
		Mr. C1	Son (59)	Married	No	With (since married)
		Mr. D1	Son (59)	Married	Full-time self-employed	With (since married)
		Mr. E1	Son (42)	Married	Full-time self-employed	With (moved into son's house)
		Mrs. F1	Daughter (68)	Widow	No	With
		Mrs. G1	Daughter (63)	Married	No	With (moved into daughter's house)
	L I	Mrs. H1	Daughter (49)	Married	Full-time	Apart (moved into downstairs of daughter's house)
		Miss. I1	Daughter (59)	Single	No	With (all their life)
		Mr. J1	Husband (78)	Married	No	With
		Mrs. K1	Niece (53)	Married	No	With (moved into niece's house)
		Mrs. L1	Daughter-in-law (44)	Married	Full-time self-employed	With (moved into son's house)
		Mr. M1	Grandson (29)	Married	Full-time	With
		Miss. N1	Daughter (48)	Single	No	With
Suwon	H I	Mrs. A2	Wife (80)	Married	No	With
		Mrs. B2	Wife (72)	Married	No	With
		Mrs. C2	Daughter-in-law (48)	Married	Full-time self-employed	With (since married)
		Mr. D2	Son (67)	Married	No	With (since married)
		Mrs. E2	Daughter-in-law (55)	Married	No	With (moved into son's house)
		Mr. F2	Son (52)	Married	Self-employed	With (since married)
		Mrs. G2	Daughter-in-law (39)	Married	No	With (since married)
	L I	Mr. H2	Nephew (40)	Widower	Full-time	With
		Mrs. I2	Daughter (52)	Widow	Part-time	With (all their life)
		Mrs. J2	Daughter (42)	Single (divorced)	Part-time	With (moved into daughter's house)
		Mrs. K2	Wife (77)	Married	No	With
		Mrs. L2	Daughter (60)	Married	No	With (moved into daughter's house)
		Mrs. M2	Daughter (61)	Married but live separately	No	With (moved into daughter's house)
		Mrs. N2	Daughter (44)	Married but live separately	Part-time	With (moved into daughter's house)

Living arrangements

Most of the carers live with their relatives with dementia except Mrs. H1's mother, who moved in downstairs at Mrs H1's house. In Korea, eight carers (three in Seoul, five in Suwon) lived with their parents with dementia after marriage or have been living together all their lives.

"I am the only son, so after I got married I lived with my mother for 37 years" (Mr. D1).

"I got married recently and so I have been living with my mother. She really dislikes being separated from me" (Mrs. I2).

12.4 per cent of adult children said that childcare and domestic help is the reason why they co-reside with their parents (Jeung et al., 2005: 29). In my sample, two carers live with their relatives because they are able to receive practical help such as domestic work and childcare.

"My wife died from a problem with her thyroid glands. I was separated from her through death. My aunt (who lived very near my house) looked after my children" (Mr. H2).

Eleven Korean older people with dementia, particularly six in Seoul and five in Suwon, moved into their carers' house when they needed care.

“She(mother-in-law) often fought with neighbours or left the house after putting something on the fire, or was sometimes found wandering from place to place. ...The landlord was worried about her starting a fire, so she strongly recommended that my mother-in-law should be sent to hospital” (Mrs. L1).

“My mum lived in the countryside until two years ago. She badly hurt her waist because she fell over a doorstep. So I took her into my house because the symptoms got worse” (Mrs. N2).

Two of the carers became carers because the spouses of the older people with dementia who used be the primary carers died.

“My father died due to cancer caused by stress in taking care of my mum. He was very healthy before that. After I got back from Japan, I had to look after her” (Miss. N1).

“My husband is the eldest. So when my father-in-law, who took care of my mother-in-law died from cancer of the colon, we decided to live together” (Mrs. E2).

Three of the carers said that their older relatives with dementia moved into their house because of conflict with other family members or the heavy burden of caring for them if they lived somewhere else.

“We have lived together since the year before last. My mum lived with my elder sister in K city but she disliked it. So I took her in” (Mrs. J2).

“My brother took my mum and aunt into his house and cared for them for three years, but he found this very difficult. Now, I am taking care of her (aunt)” (Mrs. K1).

Korean carers tend to live with their relatives who have dementia. The majority of the older people with dementia move into their carers' house. Some of them have lived together for their whole lives.

Family Care: Practical Care, Financial Care and Cognitive Care

According to Jeung and others (2005), older people who get support from their adult children receive financial support (78.1%), emotional support (76.1 %) and practical support (75.7%). In the case of older people with dementia, comprehensive care is required. Older people with dementia receive not only practical support but also emotional and financial support. Most carers live with their relatives who have dementia, and therefore, they provide all the care with formal²³ or informal care support.

“The current difficulty I have is knowing which kinds of food are good for him” (Mrs. G1).

“As a daughter-in-law, I do everything, even caring for mother-in-law's urine and feces, preparing meals and doing the housework. ... My mother-in-law has no recognition of me but still has feelings of pleasure or displeasure, so I try to make her feel happy” (Mrs. E2).

Although most care is provided by female carers, some male carers also provide practical care. Mr. C1's wife had a full-time job and

²³ In Korea, there are community care to support older people with dementia and their carers. In Seoul (2007), there are home helps services, day care centre respite care available for older people with dementia. In Suwon (pilot scheme), home care services such as assistant visit, help with daily lives, bath, day and night care, respite care etc. (Further discussion on community care will show in chapter 5).

therefore, he, who was unemployed, had to look after his mother most of the time. In the case of Mr. E1, he participated in caring for his mother, for example by taking her to hospital and searching for service information, etc.

“My wife has a job, so I look after my mother and stay close to her. But as you know, my mother is a woman so I cannot wash her, so washing is my wife’s work” (Mr. C1).

“Most of the care is conducted by my wife, but I usually take my mother from my house to hospital. In addition, I try to search for services for my mother” (Mr. E1).

“My wife owns a small business, so I take care of my mother” (Mr. F2).

In terms of financial support, Korean older people receive income mainly from their family, especially those aged 75 and over, because the pension system was recently introduced and the social assistance is attached to a strict means-test²⁴.

²⁴ Korean income security is based mainly on the social insurance and social assistance, as shown in Table 4-3. There are four public pension programmes: National Pension (NP), Government Employees’ Pension (GEP), Military Personnel Pension (MPP) and the Private School Teachers’ Pension (PSTP). In the case of social assistance, there is National Basic Livelihood Security (NBLS) and Basic Old Age Pension (BOAP), which has replaced the Elder Respect Pension (ERP).

Income security system in Korea

Income security	Earning-related compulsory pensions	National Pension	Government Employees’ Pension	Military Personnel Pension	Private School Teachers’ Pension
	Social Assistance (3.2% of total population)	- Elder Respect Pension (2007) → Basic Old Age Pension (2008 enforced) - National Basic Livelihood Security			

Table 4-3 illustrates the income sources of older people in Korea. According to the table, most older people in Korea receive an income from state benefits and family support. In detail, 92 per cent of older people receive state benefits, 78.6 per cent receive family or social support, 12.5 per cent have property, investment income or personal private pensions, and in the case of work or business income, only 8.9 per cent receive this because most are retired.

Despite a higher percentage of people receiving state benefits, the amount of money is very small compared to living expenses, for example, the average income from state benefits is ₩92,000 (£46) per month for people aged 75 or over. Moreover, people aged 75 or over receive lower social insurance pensions than other age groups because of the absence or short history of the national pension during their working life. However, the level of social insurance pensions is higher for people aged 75 or over compared to other age groups, because they also receive Government Employees' Pension, Military Personnel Pension or Private School Teachers' Pension rather than the National Pension, because of the absence of National Pension. Furthermore, GEP, MPP and PSTP have a higher rate and a longer history than the NP. In terms of social assistance, people aged 75 or over receive ₩213,000 (£106.50) per month. In the case of family support, the average amount of money received is ₩170,000 (£85) per month.

In terms of level of income, the highest income resource is investment income, which is ₩851,000 (£425.50) per month for those aged 75 or over. However, only 10.7 per cent of people aged 75 or over have a private capital income, which includes property, investment and personal private pension income. People aged 75 or over who are still working or doing business make up 12.6 per cent and the main reason why they are still working is financial. Moreover, more than half of older people feel they are in a difficult economic situation (Jeung et al., 2005: 43).

Table 4- 3 Income sources of older people in Korea Per month ₩10,000

Income Sources	Total		65-69		70-74		Over 75		Number of people
	₩	%	₩	%	₩	%	₩	%	
Working Income	56.6	14.1	66.7	21.0	45.2	14.1	31.8	5.0	427
Business or Side Business Income	52.6	14.4	68.5	19.5	38.4	14.4	24.5	7.6	436
Sub-total	56.0	27.8	70.2	38.9	42.3	28.0	27.4	12.6	841
Property Income	61.0	8.9	78.3	10.2	47.0	8.6	44.9	7.3	267
Investment Income	49.1	4.5	31.9	5.0	39.4	4.0	85.1	4.2	128
Personal Private Pension	32.7	0.4	25.6	0.8	20.0	0.1	80.0	0.1	11
Sub-total	61.0	12.5	67.8	14.2	48.8	11.8	62.0	10.7	377
Social Insurance Pensions (Contribution)	54.0	13.9	47.9	20.3	59.5	13.3	69.1	6.1	421
Other Social Insurance Benefits (Contribution)	55.9	0.2	83.0	0.1	50.2	0.2	53.3	0.2	5
Elder Respect Pension (Means-tested)	4.1	12.8	4.2	4.7	4.0	15.9	4.1	20.6	388
National Basic Livelihood Security (Means-tested)	18.9	8.6	15.9	4.9	18.0	10.0	21.3	12.1	260
Traffic Allowance (Demogrant)	1.0	89.7	0.9	76.7	1.0	98.3	1.0	98.5	2,717
Honour of War Participation Allowance (Demogrant)	5.9	4.9	13.4	0.4	5.6	8.2	5.6	7.6	149
Sub-total	11.8	92.6	13.9	83.2	11.9	98.7	9.2	99.0	2,805
Family Support	17.3	76.9	17.9	73.4	16.8	77.2	17.0	81.3	2,327
Charity Support	12.6	1.0	7.2	0.5	16.0	1.8	9.7	0.9	30
Other Income	8.4	5.4	7.7	6.4	5.2	5.0	13.4	4.4	161
Sub-total	17.6	78.6	18.1	75.6	17.1	78.7	17.5	82.5	2,381
Sub Summary	48.6	99.7	64.1	99.0	43.2	100.0	33.7	100.0	3,016
Total number of people		3,029.0		1,215.0		902.0		912.0	

Note: Multiple answers. This data excludes people who answered that they do not have any income.

Source: Jeung et al., 2005, Living profiles of older people, p. 347, 355.

Likewise, most Korean older people in this study do not have a regular income from pensions or other state benefits, except those in the lower income group. In the case of the higher income group, only one person in this study receives a widow's pension. Mr. E1's mother receives a widow's pension from his father.

"My mother receives a widow's pension from my father's pension. He used to be a teacher" (Mr. E1).

In Suwon, two of the older people with dementia receive a Honour of War Participation Allowance. The husbands of Mrs. B2 and Mrs. A2 received around £25 per month. It is just pocket money for them.

In the case of the lower income group in Seoul and Suwon, older people with dementia receive social assistance for living expenses but some only receive pocket money because their adult children have an income.

"Although my mum is a beneficiary for social assistance, she receives just 50 thousand won (£25 per month) because my income reaches 2 million won. So the expenses of caring for my mum have to come from my earnings" (Mrs. H1).

"The amount of my mother's benefit (social assistance) is very limited because my family's income is high (but interviewee's husband does not give any living expenses for his family and mother-in-law). In this situation, I cover all the expenses of caring for my mum" (Mrs. N2).

Four cases (two in Seoul, two in Suwon) receive a regular income from their property. Mr. B1 in Seoul receives an income from his

property in Seoul but his wife, who has dementia, relies entirely on his income. Mrs A1's parents have a small house in the country and so they receive rent from them, but it is only around £50 per month. In the case of Mrs E2's mother-in-law and Mrs B2's husband in Suwon, they also receive rent from properties. However, the rest of the older people with dementia in the higher income group do not have any private income.

There are different reasons why Korean older people with dementia are poor. Firstly, immaturity and under-development of the public pension and income security; secondly, older people do not invest money for their retirement. Mrs. G1 explained that in the past, there was no state support.

“There was no state support at all in the past. Most older people were not entitled to a pension due to the non-existence of pensions at that time” (Mrs. G1).

Some Korean carers mentioned that the state should provide fiscal support for older people, but they still do not feel that income security should be a social right.

“I never think of state income support as a social right. I do not expect the state to provide all the support for older people, but I do think the state should provide some support” (Mrs.G1).

“I think the family and the state should share the responsibility of caring for older people. There are some wealthy families and some poor families. ... There are

many older people who do not receive support from their family” (Mrs. N2).

Moreover, some carers point out that older people gave all of their money to their children and, as a result, are now poor.

“We were not a wealthy family. But we believed that the most important thing was to invest in our children’s education. We invested all our money for their education and for their futures. However, there is nothing left for us. I regret this” (Mrs. A2).

Traditionally, the eldest son looks after the parents, and thus many older people’s inheritance leaves the property to the children.

“A long time ago, my parents-in-law left their property to their oldest son. They thought their older son would provide their care when they became older. However, the older son did not provide any care for her. I am the youngest son’s wife and I look after my mother-in-law” (Mrs. G2).

Older people with dementia therefore rely on their family, particularly their adult children. However, the money from the family is not a proper income that can maintain their daily life but is only enough to be used as pocket money. Kwon (2001) also argues that family financial participation cannot help older people to ‘escape poverty’. Moreover, many carers live with older people with dementia and are responsible for all the associated expenses. Therefore, most older people with dementia do not receive any money.

In the case of cognitive care, Korean carers provide emotional support to older people with dementia. Mrs. G1 considers the emotional feelings she has for her father, and says she expresses her love towards him through a warm relationship.

“I as a daughter have a good relationship with my father and help him exercise often. ... At the moment, he laughs cheerfully. I think a good relationship is very important” (Mrs. G1).

However, most carers make decisions without the older people's opinion being taken into account, due to problems with cognition. There is no Power of Attorney system for older people with dementia in Korea. The power of attorney system provides an opportunity to process older people's will before they lose capacity. The power of attorney system may not be a perfect system for decision-making for older people with dementia but it still provides a chance to continue their will. It means that Korean older people could not have any opportunity to participate in decisions about their well-being, finance or property.

Korean carers in this study provided a variety of care for their relatives with dementia. In fact, most carers live together and, as a result, provide not only practical care but also financial and cognitive care. In the case of financial care, most older people with dementia rely entirely on their family's income in the higher income group, due to immaturity of the public pension system. On the other hand, older

people in the lower income group receive public benefits, but the amount of money is relatively small and often does not allow them to escape poverty. In cognitive care, decision-making is usually carried out by the carers, without the opinions of the older people with dementia being taken into account. As yet, there is no protection law or system in place for the opinions of older people with dementia in Korea.

Family Network

Ten out of twenty-eight carers receive help from other family members. In Seoul, Mrs. H1's aunt provides most of the personal care for her mother who has dementia. In Suwon, Mr. D2's sister takes his mother to church once a week.

"My mother moved into my house. After she came into my house, it was hard to live together. Then, I decided to take my aunt into my house. My aunt takes care of my mother. My aunt and mother had lived together since my childhood" (Mrs. H1).

"Every Sunday, my younger sister takes my mum to church" (Mr. D2).

Three family members supported the relatives financially because they live far away from the relative with dementia. However, two of the carers did not receive regular financial support from family members.

“My younger brother gives me some help such as money for nappies but he does not help me with the actual care” (Mrs. G1).

“From time to time, our children give us an allowance of pocket money, but it is not regular” (Mrs. B2).

Respite is very important for carers so that they are able to resolve their stress and renew their energy to be able to continue with the care. Three carers received help from other family members while they were on holiday.

“If I have business to attend to, my brothers and sisters come to look after her. ... I have travelled two or three times. Travelling makes me feel more energetic and I wish I could go on trips more regularly” (Miss. N1).

“Until last year, my sister was able to care for him while I was away, but now she cannot do that because she has knee problems” (Mrs. B2).

In my sample, primary carers provide most of the care for older people with dementia. Ten out of twenty-eight carers receive help from other family members in Korea. Eighteen carers (eight in Seoul, ten in Suwon) receive no regular help from other family members. Some carers have experienced conflict because no one shares the burden of care with them.

“Nobody is interested in caring for my mother-in-law, so her care is not shared equally. ... I’m disappointed” (Mrs. G2).

“There is no one else able to look after my mother-in-law. She has a serious case of dementia and so others don’t know how to care for her” (Mrs. E2).

Two carers in Suwon said that their family members did not offer any help, even though they live together, due to a lack of knowledge about dementia.

“My children dislike their grandma because she is strange in the way she talks and conducts herself. Previously, they helped me to wash my mum, but now they dislike seeing her” (Mrs. N2).

“At first, my children thought my mother-in-law just didn’t remember things. But she now has other symptoms. She spits everywhere and acts strangely. Now the children dislike their grandma” (Mrs. E2).

This shows that there is often a weak family network in Korea. The majority of carers do not receive regular support from other family members and, as a result, the care of older people with dementia is provided intensively by the primary carer.

Burdens of Carers

As mentioned above, caring for people with dementia is complex work and, as a result, carers are under stress or feel burdened. Kwon (1994) points out that the ways in which Korean carers feel burdened include: social activity restriction, negative change of recipient and carer relationship, negative change of family relationship, psychological burden, financial and job-related burden, and health related burden (Kwon, 2006: 122). This means that caring for people

with dementia affects the carer's entire life. The symptoms of dementia cause carers to feel stressed and burdened. Some of the carers explained the difficulties of caring for older relatives' with dementia, including wandering, incontinence, communication and sleepless nights, which influence their feelings of stress.

"It's impossible to communicate with my mum and so I cannot know what is wrong with her" (Miss. N1).

"The difficult thing about caring for my aunt is that she can't eat anything other than thin rice gruel because she has lost her teeth. Also, she can't relieve herself and doesn't sleep at night. I get off to sleep at 12 a.m. but she doesn't sleep until the morning" (Mr. H2).

Some carers' who have their own children said that they got stressed because of the problematic behaviour of their grandparents.

"My children were kind to their grandma and grandpa but now dislike them. For example, they suddenly open the door on the kids and this makes the children angry" (Mrs. A1).

"My eldest daughter ran away from home because her aunt behaved strangely and didn't sleep because of her dementia" (Mr. H2).

Most carers' social lives are affected by caring for older people with dementia. One carer stated that caring for older people with dementia not only influences his social life but also his employment.

"I have my own business but my mum makes things very difficult. I cannot go out in the morning or at night.

There are big problems regarding social activities” (Mr. F2).

Carers in the lower income group tend to be poor because the means-test assesses not only older people’s income but also their children’s income. One carer pointed out that the dilemma is whether to keep their job or give it up.

“If I stop work, our life will be difficult. But if I go to work, my mother cannot have meals, which makes me feel stressed” (Mrs. N2).

Most carers suffer from stress when caring for older people with dementia. This shows that many carers have problems with their health, not only physically but also psychologically.

“I cannot be annoyed at my mum. I bite my lip to suppress my anger. But later on, this makes me feel more stressed” (Mrs. N2).

“I wish I could live comfortably in my old age. Dementia prohibits communication between my husband and me. Now I’m in a state of depression. I have been taking medicine for depression for three months” (Mrs. K2).

Caring for a relative with dementia, especially when the carer is also older or a spouse, puts stress on the carer and, as a result, increases the risk of health problems, causes the functioning of the immune system to deteriorate, causes cardiovascular problems and increases physical symptoms (Mittelman et al., 2007: 780). Miss. N1 stated that her father, who was a spouse carer of an older person with dementia, died

because of cancer. Moreover, Miss. N1 pointed out that she got gastritis and cholelithiasis because of the stress of caring for her mother.

“My father died because of cancer while caring for my mother. He got very stressed because of the dementia symptoms. Caring for my mother also put me under a lot of stress, which resulted in gastritis and cholelithiasis. I had to have surgery” (Miss. N1).

Although carers experience stress and feel a heavy burden when caring for people with dementia, they try to resolve this. One carer stated that she could continue with her caring role after she made some time for herself.

“Living away from my mother-in-law makes me have a warmer attitude towards her. I wanted to have my own time and not get so stressed” (Mrs. E2).

Some carers carried out activities to reduce their stress caused by caring. Mrs. A1 started to participate in singing and dancing classes. Mrs. G1 went hiking to refresh herself.

“My personality is calm and quiet, but I suffered from depression after my mum came into my house. So I attended classes for singing and dancing, administered by the community, for five or six months. I now get rid of my stress by attending these classes” (Mrs. A1).

“I couldn’t go outside for long periods of time because of caring for my dad. ... This causes depression. I now cycle around my town to relieve my stress” (Mrs. G1).

Religious belief influences people's ability to deal with the burden of care. Some carers said that their religious belief has helped them to overcome their problems.

"Now I'm praying to get the ability to love. God gives me the power to take care of my mother-in-law" (Mrs. E2).

Korean carers in this study reported their burden of caring for people with dementia. The symptoms of dementia and lack of social activity has an effect on the burden of care. Moreover, other members of the carer's family are also distressed. The burden encourages poor health, both physically and psychologically. Carers in Korea have tried to resolve their stress of caring through social activity, respite or religious belief.

Motivation

There are various reasons why people look after their relatives with dementia. In the case of spouses, it is their love and affection, and responsibility and obligation of marriage are the motivation for caring for their spouse.

"I can't live with my husband without conjugal affection. Also I feel pity for him. My husband was very handsome and bright. Now he has totally changed and I take pity on him" (Mrs. K2).

"During my lifetime, I should take care of my husband as best as I can. This is my duty, I think" (Mrs. B2).

According to the Jeung and others (2005), 37.2 per cent of adult children who co-reside with their parents respond by saying that the reason for living together is obligation, whereas love and affection is only 9 per cent. 12.4 per cent said that they need domestic or childcare help from their parents, 10 per cent choose the lack of their parents' financial capability, and 87 per cent of carers among adult children or grandchildren say that repayment and obligation are the main reasons for providing care to their relatives with dementia.

“My mum has a notion of preferring a son to a daughter, so she was quite nice only to my brothers. However, my dad was totally different from my mum. He ran to the hospital when I was ill and gave me much love. Like my dad, I would like to do that” (Mrs. G1).

“I have a duty to take care of her because I’m her son” (Mr. E1).

Traditionally, the eldest son usually has the obligation to care for the parents in Korea. Some carers are the eldest sons, and therefore they stated that it is that obligation that is their motivation to look after their parents.

“My husband is the eldest of my family. I have been very ill, so I hope the other children will take care of them. Especially because the parents want to stay in the youngest son’s house. But my husband’s brothers and sisters said, ‘Why do I have to take care of them when there is an eldest son?’” (Mrs. E2).

Some carers provide care for their relatives with dementia even though they have a negative relationship with them, simply because there is no alternative.

“My mum and step father ill-treated me and I thought they regarded me as a maid. My hope was to be sent to an orphanage. I don’t respect or share anything with my mum. However, she gave birth to me and so my basic piety is to take care of her” (Mrs. J2).

“My mother disliked me so we fought together everyday. But I couldn’t get out of caring for because there is nobody else. I have no feelings of filial piety” (Mrs. N2).

Two carers who were the niece and nephew of an older person with dementia said they want to repay their relatives.

“I couldn’t go to school in my town because I had problems with my leg. My aunt lived in Seoul and I was sent to live with her. ... I am like her daughter” (Mrs. K1).

“My aunt has cared for my children, so it’s natural to want to take care of my aunt” (Mr. H2).

One carer said that the motivation for caring for her mother is pity.

“My mum is the eldest daughter-in-law, so she worked hard with the housework even though she had her own problems. She gave birth to just daughters. This makes her very sad and I pity her. Despite her difficult life, I would like to take care of her forever” (Mrs. L2).

Accordingly, most carers said the motivation for caring is ‘obligation’, although they had many mixed reasons for caring for their relatives in

Korea. Two carers said that love and obligation are their motivation for caring for older people with dementia.

“The motivation to support my parents is love and filial duty. ... I am the eldest son, so I feel a strong responsibility, and the others are not in a good situation to take care of my parents. In particular, my mother wants to live with me. She dislikes going to my brothers and sisters’ houses” (Mr. D2).

“I like my mum much more than my other brothers and sisters do, so it’s natural for me to take care of her. Caring for her is more convenient for me because I live alone” (Miss. N1).

The majority of carers in Korea help their relatives with dementia based on obligation or filial responsibility. However, obligation or responsibility is not their only motivation to provide care and there are various other reasons.

4.3 Summary

This section has focused on family care in Scotland and Korea. There are similarities and differences between carers of older people with dementia in Scotland and Korea. Yet, similarities are few whilst there are many differences between the two countries. Different aspects should be very closely noted, because the objective of this thesis is to identify whether the differences are as a result of culture or institution.

In the case of similarities, the carers of both countries are mostly female, especially daughters, and the majority are adult children of the older person with dementia. What is very interesting is that the motivation of caring is similar in both Korea and Scotland. The carers' motivations for providing care to their relatives include obligation and love. This shows that the motivation of Koreans who have been affected by Confucianism may not necessarily be stronger than that of Scottish people. If this is accepted, previous studies based entirely on cultural factors are unpersuasive.

There are a variety of differences in all the categories. The majority of carers are adult children of the older person with dementia in Scotland and Korea, but the employment status of carers was significantly different between Scotland and Korea. A higher portion of Scottish carers have a full- or part-time job compared to those in Korea. The reason for this is that in Scotland, there are welfare systems in place to support the carers. This implies that institutions rather than culture affects the type of care offered and standard of living.

Korean carers appear to be different from their Scottish counterparts in terms of living arrangements. Almost all Korean carers cohabit with their relatives with dementia, whilst Scottish carers less often live under the same roof. In fact, adult children in Scotland tend to live apart from their older relatives, but stay nearby. This could imply the notion of the culture phenomenon. However, it seems that

older people with dementia have their own homes and a regular income in Scotland. Likewise, economic independence influences independent living arrangements among older people with dementia. Moreover, the majority of Korean carers used to live separately from their relatives before the diagnosis of dementia was made. This shows the change in family structure in Korea. Therefore, this study cannot say that culture is the strong determinant that supports the different living arrangements in Scotland and Korea.

On the other hand, Scottish older people with dementia tend to receive less financial support from their relatives or adult children than their Korean counterparts. Korean older people are not financially independent compared to Scottish older people, because most Korean older people who are over 75 do not receive a regular income from pensions or allowances, apart from beneficiaries or social assistance. Moreover, family financial support from their relatives is often just pocket money. Kwon (2001) discovered that private (family) transfers in Korea are higher and public transfers are drastically smaller compared to those in the UK. Some researchers have said that this phenomenon of financial care in Korea is based on the cultural aspect. However, Kwon argues that the private transfer may not continue because of changes in family structure and relationships. Moreover, his study shows that the amount of money in private transfer is too small to save older people from poverty. The result of my research is consistent with Kwon's conclusion. Likewise,

the greater financial support from family in Korea seems to result from poor institutional situation of social welfare rather than culture.

In addition, there was a considerably different family network between the two countries. Generally, carers in Scotland and Korea received a similar type of help from other family members such as respite care, practical care, emotional support, etc. However, most Scottish carers received help from other family members whilst only a few Korean carers received help. Moreover, Scottish carers received regular help from family members, for example, other family members visited once a week. It seems that caring for older people with dementia is concentrated on the primary carers in Korea due to a weakness in the family network, whilst the care in Scotland is shared between family members because of the relatively strong family network, as shown in this study. Likewise, it could be assumed that the Korean family network would be stronger than in Scotland, however, the family network in Scotland seems tighter. This may show that culture is not the dominant factor in explaining Korea's care for older people with dementia.

Although there are burdens and stresses associated with caring for older people with a disease, the difficulties of caring for older people with dementia seem greater in Korea than in Scotland. Previous studies also show that Korean carers suffer higher levels of depression and poorer health conditions than Western carers (Kim, 2001; Youn et al., 1999). They point out that the cause lies in

Confucian tradition. From the point of view of this thesis, higher burden of carers has resulted mainly from living arrangements and a weak family network. However, the reason why Korean carers live together and face the burden of 24-7 care is due to a poor social welfare system. Therefore, the finding of this study is different from the previous studies. It means that poor social welfare system has caused higher burden of carers rather than Confucian tradition in Korea.

As can be seen from this study, it is the institutional differences between Scotland and Korea rather than cultural differences that create different attitudes towards caring for older people with dementia. In other words, it is difficult for this study to identify strong evidence about the importance of culture in explaining the differences between the two countries. Therefore, it can be maintained that the cultural factor has been exaggerated in previous East Asian studies.

Chapter 5. Community Care²⁵ for Older people with Dementia in Scotland and Korea

There will be an examination of formal care, especially community care, for older people with dementia in this chapter. Ham (1999) argues that a crucial point of dementia management is to keep persons with dementia at home as long as possible (Teel & Carson, 2003:41-42). Butterworth (1995) asserts that ‘carers should feel supported and able to count on the regularity and continuity of services’ to maintain older people with dementia in the community (p. 129). Community care can play a significant role with family carers continuing to provide care. Community services for family carers and older people with dementia prevent institutionalisation and keep older people with dementia at home (ibid. 50). Furthermore, some commentators said that a lack of social support results in abuse for older people with dementia in domestic settings (Pritchard, 1999; Phillips *et al.*, 2000;

²⁵ ‘Community care means providing the right level of intervention and support to enable to achieve maximum independence and control over their own lives.... These services form part of a spectrum of care, ranging from domiciliary support provided to people in their own homes, strengthened by the availability of respite care and day care for those with more intensive care needs, through sheltered housing, group homes and hostels where increasing levels of care are available, to residential care and nursing homes and long-stay hospital care for those for whom other forms of care are no longer enough’ (Department of Health, 1989:9; quoted in Means *et al.*, 2003:7). Accordingly, ‘community care’ refers to various services such as institutional and non-institutional services. This study agrees with the definition of community care from the Department of Health, 1989. However, hospital and residential home provision used be excluded in community care (Means *et al.*, 2003:5). In Korea, residential care is usually based outside a city with a bigger sized institutional setting, thus, there are some debates about definitions of community care in practice. Thus, this study considers community care as a non-institutional setting, more specifically home based services, day care, and respite care, etc.

Lee, 2008). Likewise, community care is important not only for carers but also for older people with dementia. This chapter, thus, investigates the utilisation of community care for older people with dementia in Scotland and Korea.

The utilisation of community care is affected by social policy and culture. For example, the UK has a long history of social welfare compared to Korea. In addition, Scotland has free personal care (2002) which is a universal service for older people, whilst Korea has introduced LTCI (2008) very recently but people still must pay service charges. As a result, the differences in community care at home affect the life of carers and older people with dementia. Social policy affects the accessibility and affordability of using services. On the other hand, cultural differences influence the utilisation of social care for older people with dementia at home. The stigma attached to care services used in the Confucian society is explored in previous studies. In Korea, it used to be obligatory for adult children to look after their frail older parents. Thus, there could be the existence of different attitudes towards the utilisation of community care services in Scotland and Korea.

There are three sub-sections in this chapter. The first section describes the community care system in Scotland and Korea to show the difference in the welfare systems. Carers' attitudes towards utilisation of community services in Scotland and Korea are investigated in the second section and third section respectively. In

Korea, carers' attitudes may be different in Seoul and Suwon due to a different care system. Suwon city had a pilot scheme of LTCI but Seoul did not have the scheme in 2007. The second and third section will focus on the accessibility of service information, delivery of services and the actual utilisation of services. Finally, there are evaluations of the community services from the carers' perspective.

5.1 Community Care System in Scotland and Korea

Community Care Services for Older People with Dementia and Carers in Scotland

Following the Beveridge and Attlee Government, the 'welfare state' was created in Britain. Despite the NA providing social services for older people, social services had not been developed as significantly and comprehensively as income security and health care from 1945 to 1950. The first Labour government believed that the needs of social services were solved if the state had provided the adequate provision of income security (Baldock, 1994: 178).

In the 60s and 70s, the government became concerned about community care for older people due to an ageing population and the rising expenditure for the NHS (Lowe, 2005). In this context, there

was the introduction of the Health Service and Public Health Act in 1968. However, community care was limited to the patients who had needs for nursing care after discharging from a hospital (Evandrou et al., 1990). In Scotland, the Social Work (Scotland) Act was established in the same year. The Social Work (Scotland) Act brought about the creation of a comprehensive social service through the Social Work Department in Scotland. The law was based on Kilbrandon's²⁶ report (1964), which was published 4 years earlier than Seebohm's report. The Kilbrandon report created a unique pattern of social services in Scotland. The 1968 Act symbolised a difference in social policy between Scotland and the rest of the UK (Wood, 2008:8). Moreover, the Chronically Sick and Disabled Persons Act 1970 brought additional responsibilities on local authorities regarding the assessment of needs and the arrangement of social services for people that were chronically sick and had a disability (ibid. 182).

Thatcher's government reconstructed social policy based on 'Neo-liberalism' in order to achieve the key goal to 'roll back the frontiers of the state' and 'end of the culture of dependency' (Wikeley & Ogus, 2002:6). The Conservative government insisted on community care rather than institutional care in order to reduce public expenditure and the state's role. The Audit Commission Report, *Making a Reality out of Community Care in 1986*, emphasised that

26 Cooper explains "the proposals as opening up a fair, humane and holistic approach to children in need" (Wood, 2008: 8). Although it focuses on the childcare provisions, it provides significant momentum for the development of comprehensive and professional social services (ibid.).

‘the growing residential and nursing home care was detracting severely from the development of services for people living in their own homes’ (Wood, 2008:180). In 1988, the Griffiths Report, *Community Care: An Agenda for Action*, was published. The government responded to Griffiths with a White Paper, *Caring for people-community care in the next decade and beyond*, in 1989. It did not accept all recommendations from Griffiths’ Report but responded to the key recommendations²⁷ (Race, 2002:106). The NHS and Community Care Act was enacted and enforced in 1990 and 1993 respectively. The Act promoted community care as the preferred option for vulnerable people (Means et al., 2003; Alcock, 2003). After the Disabled Persons (Services, Consultation and Representation) Act 1986, local authorities became responsible for the assessment of disabled people, their carers and representatives. It was the first assessment which included the value of the carers’ role. In 1995, the Carers (Recognition and Services) Act was established for the assessment of carers’ own needs. Furthermore, the Community Care (Direct Payment) Act 1996 introduced cash payments to purchase the services and facilities (Wood, 2008:182).

27 ‘Key Recommendations of the Griffiths Report were: Local Authority Social Service Departments should be responsible for identifying people with community care needs in their area and for negotiating with other authorities the contribution they would make to an individual’s care and support needs. Assessment and Care Management, and the purchasing and provision of services to maintain or establish people in their own homes who might otherwise need to have institutional care, should be new powers added to Local Authority Social Services. An interactive planning relationship between Social Service Authorities, Health Authorities and other service-providing agencies was required. A minister of State within the Department of Health should take responsibility for community care.’ (Race, 2002: 106).

When New Labour came to power in 1997, Blair announced ‘The Third Way’, which rejected the approaches of both ‘pro-market’ and ‘monopolistic state services’ for policy development. However, New Labour did not change the social policy fundamentally but followed the trends of the Thatcher government (Alcock, 2003:11). The government has continued the extended role for means-testing which targets state support for those most in need (ibid. 29).

On the other hand, The Scottish Parliament in 2001 reversed the earlier decision of England not to implement the recommendation from the Royal Commission on Long Term Care (Sutherland Report, 1999) for free personal care. It is regarded as one of the first major achievements of devolution (Petch, 2003:133). The Regulation of Care (Scotland) Act 2001 was established according to Sutherland’s recommendation. It provided a new framework for inspecting care services to improve and standardise them. Finally, the Scottish Commission for the Regulation of Care (Care Commission) was established (Wood, 2008:180-181). Moreover, universal free personal care for those over 65 was implemented in July 2002 under the Community Care and Health (Scotland) Act 2002. Therefore, older people who are at home receive ‘free personal care, and in a nursing home receive ‘free personal and nursing care’.

More recent legislation has provided the Adult Support and Protection (Scotland) Act 2007 to protect vulnerable adults at risk of harm (Wood, 2008:183). The Alzheimer Society’s report, ‘The

Dementia Epidemic – where Scotland is now and the challenge ahead’, stresses the scale of the problem of dementia in Scotland. The Scottish government then announced ‘Mental Health in Scotland Dementia: A National Priority’ in 2008 (The Scottish Government, 2008). It not only concerns diagnosis and services but also researches dementia. It provides a multi-full approach to improvements of dementia in Scotland²⁸. It is a very inspirational government plan for dementia.

The Scottish government implemented universal free personal care for older people. Free personal care provides for people who need personal care and are aged 65 or over without a means test. It is based on general taxation. Older people with dementia could receive free personal care in kind services or direct payment²⁹. Only Scotland provides free personal care in the UK. The free personal services include (The Scotland Government, 2001):

²⁸ In England, the National Dementia Strategy was published in 2009. It provides a landmark for dementia care. It is a ‘5 year plan for improving health and social care services in England’ for people with dementia, their carers and families (DH, 2009). It also emphasises better knowledge, early diagnosis and better services according to their needs. There are 17 strategy objects to achieve with in 5 years for dementia (see Appendix. 1).

²⁹ ‘Local authorities can give people cash payments as an alternative to directly arranging community care services. From July 2003 in Scotland, it is mandatory for a direct payment to be offered to you. You can choose to employ a carer yourself, or use a local home care agency if you do not wish to take on the responsibility of being an employer. You may find that there is a support group in your area to help people with managing direct payments. To get a direct payment you have to be able to manage the payments, alone or with assistance. In Scotland from June 2003, people who manage your affairs, such as an attorney or guardian, can have a direct payment. They cannot be used to pay a spouse or close relative in the same household. The local authority has to monitor that the money is being spent on the care you need. If you want a direct payment but your local authority refuses you can use the complaints procedure’ (West, 2003:109-110).

- Personal Hygiene: bathing, showering, hair washing, shaving, oral hygiene, nail care.
- Continence Management: toileting, catheter/stoma care, skin care, incontinence laundry, bed changing.
- Food and Diet: assistance with the preparation of food and assistance with the fulfilment of special dietary needs.
- Problems with Immobility: dealing with the consequences of being immobile or substantially immobile.
- Counselling and Support: behaviour management, psychological support, reminding devices.
- Simple Treatments: assistance with medication (including eye drops), application of creams and lotions, simple dressings, oxygen therapy.
- Personal Assistance: assistance with dressing, surgical appliances, prostheses, mechanical and manual aids. Assistant to get up and go to bed. Transfers including the use of a hoist.

In order to receive the community care services, care managers in Scotland assess their clients' needs, particularly the needs of clients, carer assessments and financial assessments. A care manager makes a care plan according to the assessed needs. The care plan is one of the

significant aspects that enable the clients and carers to receive proper care and services for their dignity and quality of life. Care planning should be flexible and responsible; it should recognise a client's choice and carer's needs and should be practical and link with appropriate services (Alzheimer Scotland, 2004). These services are as follows (ibid.): free personal care, help at home with housework and shopping, short breaks/respite care³⁰, home adaptations which include disabled aids and equipment, meals, alarm systems to get help, information about local services, day care, transport to and from day care, advocacy services, befriending services and holiday services, etc.

Personal care at home is free for people aged 65 and over in their own home, but 'they can be charged for domestic services such as help with shopping or housework but any charge would be subject to a financial assessment' (The Scotland Government, 2006)³¹. They can receive a direct payment for free personal care which is 145 pounds per week in 2007. Apart from free personal care, the linking services fee varies depending on the local authority (Alzheimer Scotland, 2009b). Some of the services that might be paid for depend

³⁰ 'If the local authority arranges short periods in a care home, it can charge in one of two ways as long as the stay is less than eight weeks. It can either choose to have a 'set' charge which must be reasonable, or it can use the means test used to calculate the charge for care homes. The value of your home will be ignored as it counts as a temporary stay. If your care break is in hospital, arranged by the NHS, or is part of Intermediate Care, it will be free. Benefits may be affected depending on how frequent your care is and how long it lasts' (West, 2003:112).

³¹ 'In the case of care homes, people aged 65 or over who live in care homes can receive a weekly payment for their personal and nursing care. This weekly FPC payment was set at £145 from 1 July 2002, rising to £149 from 1 April 2008 and £153 from 1 April 2009. This weekly FNC payment was set at £65 from 1 July 2002, rising to £67 from 1 April 2008 and £69 from the 1 April 2009. They still can be charged the 'hotel' costs according to their financial assessment'(The Scotland Government, 2006).

on the postcode or means-test (Bell & Bowes, 2006:6), for example, housing support depends on means-test, day care is paid the fee which depends on day care centre, respite care is totally free or paid hotel fee according to means-test.

Community Care Services for Older People with Dementia and Carers in Korea

Before introduction of the present community care services for older people in 2007, I will relate the history of community care services for older people in relation to general social policy history in Korea.

The development of social policy is divided into three stages: authoritarian government (~1986), after democratisation (1987~1996) and after economic crisis (1997~) in the development of social policies (see Appendix 2).

Welfare policies were first introduced to legitimise a military authoritarian government. The welfare policies were established negatively under ‘development first, distribution later’. In a similar vein, social policies for older people were ignored (Kim, 2004:30). In 1981, the Elderly Welfare Law was enacted, but the act was not mandatory. During this period, there was no serious recognition for ageing.

Social Policy expanded after Democratisation in 1987. Social policies were expanded in order to respond to people’s need and to

control the labour movement. In fact, no political party could avoid growth of social policy due to awareness of voting in the presidential election. In the same vein, the government also began to have positive attitudes toward policies for older persons.

The Elderly Welfare Law had its first whole amendment in 1989 which produced the old age allowance, limited to those under the poverty line (Kim, 2004:42-43). In the case of social service, there were some changes for community care. In 1987, community care services began as a form of home-help service. From 1987 to 1992, the government ensured that non-governmental welfare agencies offered home help and adult day-care services for physically and mentally disabled older people living under the poverty line. In 1993, the Elderly Welfare Law divided community care services into three types of service: home help, adult day-care and short-stay care (respite care). Statutory community care services were limited to low income older people, even though ageing population problems began to cause social problems (Choi, 2002).

Since 1997, social security has developed rapidly due to the Economic Crisis. Moreover, the social welfare such as the national pensions began to mature in this period. The growth of social welfare also contributed to social policy for older people. It demanded the foundation of measures for ageing problems in the economic crisis (Kim, 2004:45). Demographic ageing and long life expectancy were the result of the increase in chronic and long-term care diseases. Thus,

caring for older people has emerged as one of the most challenging issues in this phase. 'Long-Term Care Insurance' was enacted and implemented in 2007 and 2008 respectively.

Community care system in 2007

Home care services were started in the middle of the 1980s by voluntary organisations. In 1993, the Korean Government implemented home care services for frail older people according to the amended Older Persons Welfare Act. There are three components to social care services: home help services, day care services, and short stay services, whilst visiting nursing services are not included in the law (Sunwoo, 2001:26). Home help services include domestic support services, personal care services, and companionship services. Services in day care centres include rehabilitative services for recovering Activities of Daily Living (hereafter ADLs), meals, bathing, and recreation activity services. The limited period for short stay care for eligible older people is 90 days at a time or a maximum of 180 days a year in a place from July 2007. It used be 45 days at a time or a maximum of 90 days a year in a place before July 2007.

Table 5- 1 Social Services in Korea

1 pound=2,000 won

Classification	Services	Fee Ceiling	Recipient
Home Help Services	-preparing meals, shopping, cleaning, etc. -self-care -telephoning, conversing, writing letters, etc.	200,000	<ul style="list-style-type: none"> • Free care: entitled to NBLS and aged 65 or over • Actual cost of care: <ul style="list-style-type: none"> - Aged 65 or over in lower income than average income of workers in city: monthly average income of a person ₩ 1,013,000 ⇒ monthly average income of workers in city 3,423,000/average number of family in a household: 3.38 in 2006 (national statistic) - Charge actual cost according to services • Charged care: Aged 60 or over
Day Care Centre	ADLs rehabilitation programme, meals, bathing, recreation activity, etc.	250,000	
Short Stay Care (respite care)	Meals, nursing care, personal care	450,000	

Source: Ministry of Health and Welfare (hereafter MHW), 2007, Guidance of Elderly Health and Welfare Programme, pp. 185-193.

These services are free for aged recipients of public assistance. The poor aged can use the services at reduced cost, while others have to pay the whole costs. The government gives grants for home help services for the low income aged, such as housekeeping services, meal services, bathing services, consultation, companionship services, and visiting nursing care services. Most social care services are provided by the voluntary sector except for some professional care services. The budgets of services are provided by local (60%) and central government (40%). Although home care services give protection aid to frail older people, most socially disadvantaged people do not use

them because the coverage of benefits are only for the lowest income people.

Visiting nursing services has been a pilot project since 1994 and not been included in the Older Persons Welfare Act. Nonetheless, these are core services for frail older people in home care services. The Korean Government implemented this pilot project aimed at leading long-term care patients and after operation patients to early discharge. 75 per cent of service users are aged 60 or over (Choi & Jang, 2007). Visiting nursing services are provided by four different organisations, Public Health Centres, Korean Nurses Association, Social Welfare Organisation and Special General Hospital in University. Each organisation has different charges for services for medical treatment, consultation, nursing care and health education.

The meals on wheels service also developed from a voluntary organisation, then the Korean government started to provide this services for lower income bracket people who had a disability or illness in 2000. Some older people in long-term care could get this service.

In 2007, the government introduced the Elderly Care Voucher³² for frail older people (with dementia, strokes, infirmities, etc.) in the lower and middle-income bracket but not in NBLS. The

³² Eligibility standard: those with 150% (one person household: ₩1,781,000 in 2006) or less of national average household income (15,000 persons) *except, people who are already receive free social services, get services from pilot long-term care project services, in care facilities and are granted by government. Co-payment per month: ₩18,000~48,000, Service hours: 27~38 hours per month (MHWFA, 2008).

value of the voucher is about 200,000 won (100 pounds) per month and the co-payment is 18,000 (9 pounds) to 48,000 won (24 pounds) per month. The budget of the voucher sources is part local (Seoul: 50%, other areas 70%) and part central government (Seoul 50%, other areas 30%).

Long-Term Care Insurance

The Korean government addressed the long-term care system for the elderly from 2001, but the practical plan for the Long-term Care started in 2003. They had done three pilot projects up until 2007. Finally, the scheme, which was the same as the three pilot project programmes, was implemented in July 2008. Many older people with dementia and family carers will benefit from LTCI. Nonetheless, the Korean LTCI system will cover only severe patients and facility services, and exclude health and medical aspects. Moreover, there is a lack of facilities for the system to cover all older people with a long-term illness in Korea.

The subjects of LTCI are aged 65 or over and cannot live without others' help due to ageing and senile diseases. They need care at least more than 6 months and should be approved by the Committee of Care Level Screening for LTC. LTCI provides personal, nursing services, day and night services, respite care services, and care homes (MHWFA, 2008:190). LTCI is one of the social insurances and is administered by MIHWAF which also manages the NHI but the funds

of LTCI operate separately from the NHI. Most services are provided by the private sector. LTCI provides mainly in-kind services but family care cash benefits are available only for special occasions, for example, older people living in areas where services and facilities are not available. Family care cash benefits are not like the carers allowance in Scotland.

On the other hand, LTCI cannot cover some social services recipients in the previous system because of the LTC level. The degree of long-term care is divided into three levels as shown in table 5-2. The levels are decided according to the assessment questionnaire. Long-term care provides for people who qualify in the grades but the grades require a higher physical disability. Therefore, the voucher programme provides services for those who are not in 1-3 grades in LTC but used to use the services.

Table 5- 2 Long Term Care Insurance in Korea

Insurance rate	Insurance bill = Health Insurance bill X rate of LTHC insurance bill Rate of insurance bill: Estimated by the Committee of LTC (under MOHW) and confirmed by Presidential decree
Co-payment	-General: Care Homes: 20%, Home Care Services: 15% -Fee Reduction: recipients of MA but not NBLS, People with income below the minimum amount MOHW set Care homes: 10%, Home Care Services: 7.5% -Free: recipients of NBLS
Level of LTC	<p>- 1st grade: Persons' daily lives completely need other persons' help; The long-term care approval score is over 95 points ex) person lies down in bed for 24hours</p> <p>- 2nd grade: Persons' daily lives substantially need other's help: The long-term care approval score is over 75-94 ex) person use wheel chair and most of day time lies down in bed</p> <p>- 3rd grade: Persons' daily lives partly need other's help: The long-term care approval score is over 55-74 ex) walk with assistance facility</p> <p>Assessment Questionnaire</p> <p>Physical function (12 items): Dressing, Washing, Brushing teeth, Eating, Bathing, Changing positions, Get up and Sitting, Mobility of Sitting, Walking out from room, Toileting, Bowel incontinent, Urine incontinent</p> <p>•Cognitive function (7 items): Short-term memory impairment, impairment of doing , Order unconscious, Date unconscious, Place unconscious, Date of birth and age unconscious, Judgement decline, Communication disorders</p> <p>•Behaviour change (14 items): Delusion, Nervous or irritated, Demolish stuff, Hallucinations/auditory hallucinations, Lost their way to somewhere, Hide money or things, Sad condition and crying, Verbal abuse/threatening behaviour, Improper dressing, Irregular sleep/day and night confusion, wandering, Filthy act, resist help, inappropriate or meaningless behaviour</p> <p>• Nursing Aid (9 items): Nursing bronchial incision, Tube feeding nutrition, Nelaton catheter care, Aspiration, Bedsore care, Topmen nursing, Oxygen therapy, Cancer pain management, Dialysis nursing</p> <p>• Rehabilitation(10 items); Movement disorders (4 items)- Right upper extremity, Right lower extremity, Left upper extremity, Right lower extremityJoint limits (6 entries)-Shoulder joint, Elbow, Wrist joints and the resin, Hip, Knee, Ankle</p>
Services	<p>- Home Care Services (1-3grade): Assisting: assistant visit: help with daily lives including bathing, recreation, housework; Bath: visit with bathing equipments & provide a bathing service; Nursing: a nurse visits a senior for services directed by MD; Day & Night Care: daily temporally service provision at a facility (ex. Daycare centre); Respite Care: respite services for a short period facility</p> <p>- Care homes Services (1&2 grade only): Provide function recovery training & assist daily lives of long-term residents in care homes exclude. Special hospitals for the elderly</p> <p>- Cash benefits (1-3grade): Family Care: Payment to recipients in case having received proper care services from family members; Special Case: Partial payment in case of receiving of LTC benefits from unregistered facilities; Hospital nursing: Partial payment for nursing services at the special hospital for seniors</p>

Source: MHWFA, 2010. LTCL.

Briefly, there are similarities and differences in community care in Scotland and Korea. Firstly, community care for older people with dementia was developed later than other social policies in Scotland and Korea. Secondly, Scotland (2002) and Korea (2007) have introduced long-term care for older people with long-term illness or disability.

On the other hand, the long-term care systems in Scotland and Korea are different. Firstly, free personal care in Scotland is a universal policy while LTCI is relatively residual and selective. The funding for the services is also different. Funding of free personal care is based on taxation while funding for long-term care in Korea is based mainly on premiums and some taxation (only for lower income bracket). Thirdly, direct payments, attendance allowances, and carer allowances are available in Scotland, unlike in Korea. Consequently, community care in Scotland has easier accessibility and higher affordability than its Korean counterpart.

5.2 Carers Attitudes towards Community Care for Dementia in Scotland

Search Information in Scotland

Information about social services is a starting point for the use of community services. Information on community services should be provided immediately and automatically when dementia is diagnosed. Carers demonstrated how they got help and who gave service information. They contacted their GP or doctor, social workers, or district nurses who are gatekeepers to getting formal help. In the case of dementia, the district nurse regularly visited them to check the patients in Scotland, thus, the district nurse had a crucial role for carers. In this study, many carers mentioned that they got day care services through district nurses.

“Social worker is very helpful. I phone her when I need to. Social worker is very good actually. Very helpful. (Did the doctor refer to social worker then the social worker assessed your mother’s needs?) Yes. Now she’s got one social worker. But in the past, we just got a social worker when anything needed to change they sent social worker out who assessed her and then...” (Mrs. M).

“Daycentre for Monday and Wednesday. She goes to daycare centre. It was done through this nursing sister” (Mr. G).

Moreover, carers stated that voluntary organisations such as the Alzheimer telephone helpline and the Voice Of Carers Across Lothian (hereafter, VOCAL) website were useful to get social services information.

“Alzheimer help line, phone them quite a lot of times. They are very good. They also send me quite a lot of literature” (Mrs. L).

“(Where do you get information?) I get in touch with VOCAL people. They are superb. That’s the organisation run by carers, previous most experienced and a lot of knowledge and for carers” (Mr. D).

Some carers complained that they did not get services information immediately or automatically, because they expected that once they consulted the GP, social worker, or district nurse they could be informed of all the help which was available. Mrs. N and Mr. D were disappointed with the social service system because they experienced difficulty in getting information.

“Social worker only came out because I went to the doctor and explained the situation. The doctor wrote to the council social work department and then social work department got in touch with me. What I do find wrong with system, it seems to me you’ve got to find out everything yourself. If you don’t ask for anything, you don’t find out” (Mrs. N).

“They (doctor) suppose to give you complete listing where to get help, social worker should be providing help for you and nursing staff from the doctor whole category of help. They didn’t. We are supposed to be a leading country in the world. I am an angry man when it comes to home and systems” (Mr. D).

Carers want to receive all the information around dementia care without any extra effort when their relatives are diagnosed with dementia. However, the practice of delivery of information does not work out according to carers' expectations. Butterworth (1995) also found the carers criticised the accessibility of information. Butterworth said, 'Caregivers have assumed that once they have been in touch with the GP or social worker they would have been informed of all the help that is available' (p. 128). This study result is consistent with Butterworth's findings.

To sum up, Scottish carers received service information in various ways, such as through their GP, doctor, social workers, district nurses and voluntary organisations. Many carers mentioned that their district nurses helped to get services, especially daycare centres. District nurses visited older people with dementia regularly to check their condition; therefore, carers felt relaxed about consulting with them. However, carers wanted to get service information without pushing the gatekeepers. They felt they should received information automatically whenever they consulted with these gatekeepers. Professionals, therefore, should provide comprehensive services information for older people with dementia and carers even though the services are available from another agency (Butterworth, 1995). Alzheimer Scotland and the Scottish government tried to improve the accessibility of information. As a result, Alzheimer Scotland

handbooks, which provide services information, are available and provided in hospitals now.

Process of delivery of Community services in Scotland

According to the Scottish carers, they get the social services through gate keepers such as GPs, doctors, district nurses, and social workers. These gatekeepers contacted the service providers in particular voluntary sectors to get the services. Miss. C's mother got services from Alzheimer Scotland where she was referred by a community nurse. Mrs. L's mother has had free personal care since being discharged from hospital.

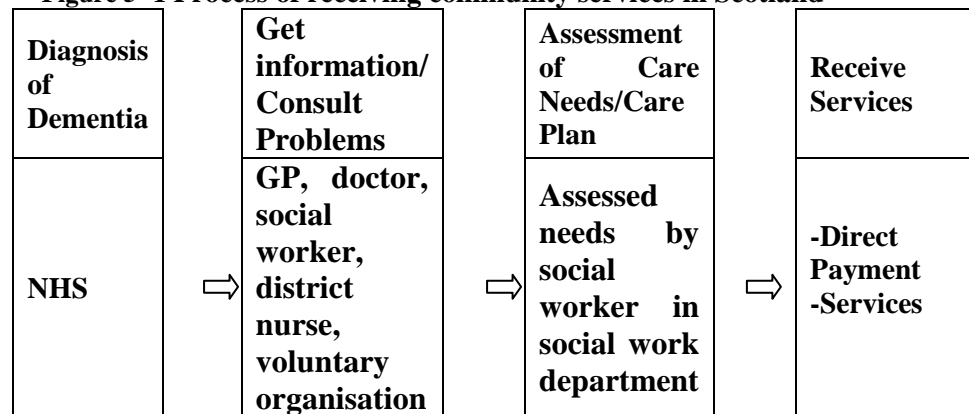
“Shortly after father died, the community dementia nurse came out to see mum. It was her put mum on the settle list of the Alzheimer Scotland. In March, the lady from Alzheimer Scotland came out and organised my mom go to on Wednesday afternoon” (Miss. C).

“(When did you get free personal care?) She gets in place when she came out from Royal Edinburgh. She is very happy about somebody coming in. She doesn't pay at all” (Mrs. L).

The process of care services in Scotland is shown in figure 5-1. According to figure 5-1, older people with dementia or carers met gate keepers to get services information or consulted on their problem, then, the gate keeper referred to a social worker or directly contacted service providers, especially daycare centres. If older people with

dementia receive personal care or a care package, they receive a needs assessment from a social worker or care manger. After the assessment, older people with dementia receive community care services.

Figure 5- 1 Process of receiving community services in Scotland



Consequently, it shows the important role of professionals in the delivery of community care services in Scotland. The professionals may cause delays to service delivery. Thus, professionals carefully assess the needs of older people with dementia and carers.

Community services at home in Scotland

There is home-based care such as home care or home help, meals services, visiting services, support for carers, day activities, equipment and adaptations to the home, respite care, alarm systems, direct payments (Knapp *et al.*, 2007:15). The percentage of people over 65 who receive home care is slightly bigger in Scotland (6.9%) than in England (6.1%) according to the Dementia UK report (Alzheimer

Scotland, 2007: 26). More expenditure on home care per head of the population over 65 in Scotland (£437.50) is spent than in England (£214.40). It is due to free personal care in Scotland. Over 42,000 people received free personal care at home in 2007. A Scottish Executive evaluation in 2007 found that free personal care assisted to support informal carers' caring roles and made a positive effect on the lives of carers and the recipients (ibid. 2007:31). The number of people with dementia who received a home care service and day care service was 3,679 and 4,232 respectively in 2006 (ibid).

In this study, Scottish carers and their relatives with dementia received various formal services as Table 5-3 shows. Some carers get formal care services not only from the public and voluntary sector but also the private sector. Carers arranged domestic services, particularly cleaning, from the private sector. All older people with dementia received at least one service. According to the interviewees, older people with dementia started being involved with a day care centre or lunch club which extended their personal care or package of care. In the case of respite care, 6 carers used respite care for holiday. There were 7 people that received free personal care and 12 older people with dementia attended a daycare centre or lunch club. There were 3 carers who received the carer's allowance.

Table 5- 3 Receiving care services in Scotland

	Case	Social Service	Remark
H I	Mrs.A	Day care centre Mon- Sat (except Fri.), free personal care: three times a day (8-9:30am, 4pm, 9pm)	Respite care for holiday, attended carer group meeting
	Mrs.B	Day care centre once a week	Carer group once a month, carer's allowance
	Miss.C	Day care centre once a week , home helper for give lunch	
	Mr.D	Day care centre on Wed. 11:30-3	Respite care, carer's allowance
	Mr.E	Day care centre two day a week, free personal care three times a day: morning, lunch time and evening (pill taking, changing and bath etc)	
	Mrs.F	Day care centre: 3 days a week (A: £4 , B: £5.5, C: £1) £10.5 per a week x 4 week (£42 a month)	
	Mr.G	Day care centre two days a week,	Private home helper for cleaning and care once a week
	Mr.H	Free personal care: four times a day	Respite care: 2 week respite care every 4 weeks
L I	Mr.I	Free personal care: four times a day	
	Mr.J	Lunch club	
	Mrs.K	Day care centre two days a week	Respite care for holiday, private home helper for house work 2 hours a week, carer's allowance
	Mrs.L	Day care centre two days a week, Free personal care: four times a day	Respite care for holiday
	Mrs.M	Day care centre once a week, free personal care: four times a day	Respite care for holiday, attended carer group meeting
	Mrs.N	Day care centre three days a week, shopping helper, free personal care: once a day at morning	

12 out of 14 older people with dementia attended daycare or lunch club. A day centre was a starting point to receive formal care. Sometimes older people were reluctant to go to a daycare centre in the beginning, but they finally became interested in going to day care.

“First of all day care, she started going to E centre once a week, after that she started going to H day care centre” (Mr. E).

“Once a week, she goes to the club. She was very resistant because she lost all her confidence because she has difficulty speaking and expressing. She was very resistant going to the club. But now she loves it. She is really getting on well with it. So we are really pleased it works out well” (Miss. C).

11 out of 14 older people with dementia received more than two care services, except Mrs. F’s husband, Mr. J’ wife and Mrs. B’s husband, who received day care services only. These three are spouses of older people with dementia. They did not get free personal care for their relatives yet, they only used day care centres. Most of them did not apply for free personal care services because they did not feel they needed it. In this context, Mrs. B said that ‘we haven’t got it yet’.

7 out of 14 older people with dementia received free personal care. Moreover, they got a package of care at home. Mr. H’s wife received free personal care services 4 times a day, including washing, dressing, bathing, putting her to a chair, changing her incontinent pad and making bed. Moreover, Mr. H received free respite care for 2 weeks every 4 weeks.

“The carers come every day, four times a day. 10 o’clock the carers come and wash and dress her, and hoist her onto a chair. Then they come at 1 o’clock, come and change Isa, then they come at 4 o’clock to

change, and put her to a chair this time. 7 o'clock they come in change and put her to bed. It's called free personal care. I think that's terrific, it doesn't cost me anything. Only I had a bath nurse on Wednesday. 18 months ago, we got free personal care. No, daycare now because she's in a big chair now. She gets to stay at home. But, in the summer, I can get somebody to put her in the wheelchair, get help for her to go for a walk down to a store and come back again may be about an hour and half or two hour. We wait for the summer weather... She is four weeks at home and she goes to respite for two weeks" (Mr. H).

Mr. H is old and the condition of his wife is severe, but he is very keen to keep his wife at home. He appreciates receiving the package of free personal care services. Moreover, the respite care and free personal care help him to continue to care for his wife at home.

The majority of people who are provided free personal services and a package of services live alone. Moreover, carers have full time jobs or part time jobs. Mr. E's mother gradually received more free personal services. Before the free personal care, he used to visit her every lunch time to check her, even though he had a full time job and lived apart from his mother. His mother got personal services three times a day. Mrs. L also had a job and lived separately from her mother. Her mother got free personal care, day care and respite care.

"She started to get evening home help services 9 month ago. ... She was just eating and taking her pills then get morning and evening so she gets somebody in the morning and evening. ... She had a fall so three times a day visit because she needed to take extra pain pills on lunchtime." (Mr. E).

“Somebody comes in morning, lunchtime and teatime (dinner) and bedtime. ... Somebody goes on Wednesday, gives her a bath. Four times a day every day. Two days, she goes on daycare. She is going to respite care several weeks later” (Mrs. L).

Mrs. M and Mrs. N also had jobs and lived separately but close. Mrs. M’s mother received free personal care, day care and a companion service from the voluntary sector. Her mother gradually received more free personal care as time went by. Mrs. N’s mother also received various services from the public sector and voluntary sector. Her mother attended a daycare centre 3 days a week and free personal carers visited her every morning for medication. She received a bath service once a week.

“She has 4 carers a day. ... It is free personal. It is excellent. Up until last summer, she just had home help then she gradually got more until she’s got four a day. Once a week for daycare centre. Two afternoons she has visitors from a charity called life care (how did you get the services from the charity?) A social worker” (Mrs. M).

“On Monday and Friday, she goes to club run by Alzheimer. On Wednesday, somebody comes in 9 o’clock in the morning to take her shopping for 2 hours and then she goes to a club. She has a carer (free personal care) comes in every morning for about 10 or 15 min. Just make sure she is clean. Tuesday and Thursday, I usually have my mum” (Mrs. N).

Mrs. A, who had a full time job and a strong motivation to care for her mother, arranged various services during her working time. She stated that, “I would give up my work if there were no social services”.

“Allowance and services come in do things for me, fill in the gaps. I have a home help comes in Mon to Fri and 8 to 9:30 get my mum to wash and dressed for daycentre, give her medication. Then she goes daycare centre around 9:30-45 and she comes back about 4. Someone comes in four and five. My husband and I come from work about five. Someone comes in the night wash, dress, and bed. It is pressure off me” (Mrs. A).

These cases show how free personal care and a package of services help to continue to keep older people with dementia at home. It also enables carers’ care at home to carry on. Moreover, free personal care makes it possible to maintain carers’ own occupations. Sometime, carers gave up their work in order to provide care but it may result in poverty for the carers later in life. Free personal care helps keep a balance in their lives and so they can care for their relatives at home.

The utilisation of respite care extends the period of community living (Levin *et al.*, 1992). Carers use respite care services during their holiday in Scotland. Carers use respite care to refresh and renew their energy to care for their relatives with dementia. Mr. G tried to use respite care but he faced a challenge from his wife because she did not agree with respite care, but finally she agreed that her husband needed a break.

“Doctor and other people said “she should have a respite”. Although she doesn’t like it in the beginning. It comes to sort of agree with that I need go away sometimes. As I said that just doesn’t help me, I reckon it does help her as well” (Mr. G).

One carer pointed out that the carer and recipient did not like respite care, and as a result they found an alternative way to get respite. Mrs. N used Alzheimer Scotland's service and got her daughter's help during her holiday.

"We were going away on holiday for 2 weeks. It was community nurse arranged for to get it. ... I dropped her off. I came out... I just didn't like it. I went back to pick her up afternoon and said "did you like it?". ... She said "no". ... So, Alzheimer took over. I gave them all my mother's money for the weeks. They phoned her every morning and my daughter lives here she came in. It worked well. We've been doing that ever since" (Mrs. N).

It is a potential issue of conflict that older people with dementia do not want to use respite care while carers need it. Some carers find other alternative ways to get a break using other family members or help from voluntary organisations. Mrs. N used more home help services and visiting services from Alzheimer Scotland while she was on holiday. Scottish carers in this study tried to listen to their relatives when they decided to use services.

To sum up, all older people with dementia received at least one service. Older people with dementia received day care (12 persons), free personal care (7 persons) and respite care (6 persons). 5 out of 14 older people with dementia had free personal care and day care services together. 6 out of 14 people had free personal care four or three times a day. 2 people received free personal care in the higher income group, while 5 people received free personal care in the lower

income group. It seems that it relates to the degree of dementia or needs of care rather than their means, because free personal care is a universal service without a means-test. Moreover, the study found that community care improves the quality of family care and helps older people with dementia stay at home as long as possible in Scotland.

Evaluation of community services in Scotland

Family carers get respite, other social activities, and domestic working during the time of day care. Mrs. F used daycare 3 days a week. She used the time for shopping. She has a lot of gratitude for daycare. According to Mrs. B, she used the time for a nice coffee break or cleaning house, which is difficult to do when her husband is with her.

“Best points I can do shopping during the daycare time. ... I ask him what you had in day care. He said ‘I hadn’t any in there’. However, it is brilliant to use daycare. My husband needs to do something” (Mrs. F).

“He goes to E Centre one morning a week. I usually go to Cafe Nero to have a coffee and buy a paper and look at the paper. Well, quite often I do things about a house, for example, bathroom for special clean. I usually go and have my hair cut” (Mrs. B).

In general, carers appreciated the day care service, but some of them felt the period of time was too short for other social activities.

“He goes to day community centre on Wednesday. He goes there from 11 o’clock back to 3 o’clock. ... I either

sleep, I either go to get a hair cut or I go for a swim. I only got 3 three hours. That's it. If you're going to town it doesn't give you much time to see friends or anything" (Mr. D).

Carers did have complaints about the short time of daycare, but all were fully aware of the help the service provided them. The interviewer asked about the waiting list for day care because a previous survey highlighted the waiting list for day care (Alzheimer Scotland, 2008). There were various situations, depending on the local authority or area where the older people lived. However, carers in this study did not mention a waiting list for day care centres. Mrs. F said that her husband got day care centre services without a long wait.

"It doesn't take long to get daycare. I was very lucky. The first one was N-daycare. One day a week. That was brilliant" (Mrs. F).

This study found that the accessibility and affordability of using daycare was not problematic. Older people with dementia paid to attend day care but carers did not feel it was expensive, because the services were subsidised by the council which provided the services with the actual fee. Moreover, all older people with dementia are entitled to receive a universal Attendance Allowance of £67.00 or £44.85 (rate in 2008) per a week.

"On Monday (day care centre), I give them 4 pounds. On Wednesday, H- Church runs community centre. ... Four pounds has got to pay for fuel and some food and

the pound (one pound) on Wednesday only goes for the food only, because council subsidises ... One Monday, they buy their own bus and fuel up by themselves. (Do you think it is expensive?) No, Not expensive" (Mr. G).

Some carers attended carers groups and they found it useful to share lessons with others.

"It is helpful. When you go to these meetings, you meet other people and share experiences" (Mrs. A).

"It was quite good. It is good to meet other people who have same problems" (Mrs. M).

In order to continue the carers' role, they needed breaks from the caring and worrying about their relative with dementia. Therefore, they used respite care. Some carers had positive attitudes towards respite care. Mr. H got regular respite care and Mrs. M used respite care for a family holiday. Carers seemed confident in using the respite care. The breaks helped them to renew their energy to keep doing their caring role.

"I don't have any time out. But I have only time out when she is in respite for a fortnight. I go down to south England, because my daughter is down there. That (respite care) is best things you have because when she goes in there I think that is terrific." (Mr. H).

"(Respite care) Was last year for the first time when I was on a holiday. That was good. I started to look myself and then social worker helped me to find the place. I just say to her she was going to go on a holiday as well. She really enjoyed it. She really liked it" (Mrs. M).

However, two carers who used respite care had bad experiences of respite care due to missing their relatives with dementia. Respite care could lead to disaster when older people with dementia go missing. In fact, every care home has a safe lock on the front door to prevent them going missing in Scotland³³, but sometimes, they can go missing due to carelessness or lack of staff. The missing experience may result in a distrust of respite care. It seemed that Mrs. A did not trust the service anymore. On the other hand, it seemed that Mrs. L liked the service, apart from fearing her relative may go missing.

“She had been respite in an old folk’s home. She was only there for 4 hours, she went out on her own. That kind of put me off” (Mrs. A).

“It (respite care) was lovely. But she actually went missing, nobody knew about her. I got a phone call from the police station. They said that “they have mum there”. So I phoned up the care home. ... Trying to get back that it was a lovely home. It was lovely place, but unfortunately it happened” (Mrs. L).

Respite care should provide precise and careful care for older people with dementia in order to prevent older people with dementia going

³³ ‘Care Standards Act 2000, 69. Subsection (3) provides that the registration authority will be able to grant an application either unconditionally or subject to such conditions as it thinks fit. Conditions may be generic or specific. For example, the registration authority will be able to impose conditions on care homes specifying the categories of patients and the number of residents that may be accommodated. In some cases a specific condition may be required to take account of the circumstances in that individual home, centre, agency, private hospital or clinic. For example, there might be a condition that a particular door be kept locked to prevent confused residents from wandering directly on to a busy road’(Office of Public Sector Information, 2000).

Source:

http://www.opsi.gov.uk/ACTS/acts2000/en/ukpgaen_20000014_en_1.htm#end

missing. Carers generally felt relief and confident after their older people with dementia received free personal services or a care package.

“I just feel more confident, she would be up in the morning and washed, and dressed and she is more oriented and always get meals” (Mrs. M).

In the previous sections, carers show the benefit of free personal care for carers and older people with dementia. Free personal care seems to help ease the lives of older people with dementia and carers and prevent them from institutionalisation. Moreover, it makes it possible for older people with dementia to live alone and their carers to keep their jobs.

However, carers had difficulty in getting the free personal services. They wrote letters for several months and tried to push the gatekeepers to provide services that they needed. Carers were very active in getting free personal services. These phenomena are caused by limited resources or budget.

“It is very hard work. I continually fight with social services to get services and places. It is not easy. Mum got lucky. I do write a lot of letters to different places and I do write to MPs about services and complain. It took a long time to set up” (Mrs. A).

“(Get services) Not easily. No, it’s a fight! Couple of months each time to get her more time” (Mrs. M).

There was a misunderstanding of free personal care. Two carers complained about being confused by the exaggeration of the term, free personal care. Mr. D complained not only about the range of free personal services, but also about the short time. The time of care services was too short to do other activity because free personal care services were based on tasks, not a full amount of time.

“I don’t understand exactly what you are getting for your free personal care. Some people seem to get home help as it comes under free personal care. They don’t pay. But they don’t do any house work. It is difficult to pin down what exactly what they do for the free care. Put the meals down to them is that free or not” (Mrs. K).

“These people are coming to assess me in busy times in the morning. I could take offer that an hour but what can you do, where do you go for an hour? I’d rather do something in the house while this guy shaves him” (Mr. D).

The delivery of services is important for the daily life of carers and recipients. However, carers had experienced trouble with service delivery when formal carers changed. Service providers should train the new formal carers to provide services without inconvenience or conflict.

“Dementia, consistency is the most important, I think as important as regular basis, that’s quite difficult to get sometimes from social services. You are fine if your regular helpers are coming in, but if anybody is going on holiday, they (other helper) forget to cover, forget to give her a wash or give a tablet” (Mrs. A).

“Both of them (formal carers) now know mum, what she needs to get done, that works pretty well. But when they are off on holiday whatever then it is not very reliable. When it changed from older to current one, there was very little communication between one carer and another” (Mr. E).

There are also issues about early bedtimes for older people. Mrs. M’s experience was that the carer came to put her mother to bed in the early evening.

“Last night, I was out. Carers meant to go between 5 o’clock and 6 o’clock and then 8:30 to 9 to put her to bed. I went around quarter past 7, she was putting my mother to bed. ... They want to get there earlier. It is not fair. She is not a child. I complain to the home carer organiser. Something goes wrong, someone goes on holiday, somebody is ill” (Mrs. M).

To achieve standard services, the quality and stability of services should be guaranteed but carers experienced instability with services on various occasions. These issues should be informed to the care providers and precisely undertake information of older people with dementia and their needs from the previous to present formal carers. The national care standard should ensure the standards of services at home. In fact, there is an inspection of services to accomplish the standard of service quality in Scotland and the result of the inspection to show the public that help carers’ decision on the choice of services provider.

In conclusion, there were positive and negative points on the service evaluation from the perspective of carers. In the case of

positive points, the services provided respite or breaks for the carers and they felt relief and confidence during the services. The services helped them to do other activities, have a social life, and do house work. On the other hand, carers complained about waiting times and misunderstood free personal care, the delivery of free personal services, the lack of services and the short-time of services. However, most carers generally felt that community services helped their caring role, but they wanted improvements for better services.

5.3 Carers Attitudes towards Community Care for Dementia in Korea

Search Information in Korea: Seoul and Suwon

In Seoul, people received information from various provisions such as general welfare centres, which provide social services, public health centres and social workers in local councils, etc.

“Before discharge from hospital, I found the name board of a welfare centre (voluntary sector funded by government) which was near my house. I never interested before so I did not know the welfare centre. But I needed help desperately so I went to welfare centre to get information about available services for my mother” (Mr. D1).

“National health centre give me information of the dementia centre” (Mrs. G1).

“My father had disability so he got help from social worker in council. At that time, the social worker gave information and search for help for my grandmother (with dementia)” (Mr. M1).

On the other hand, some carers got information from their neighbour or friend, etc.

“One of my church member’s mothers uses the respite care service. So I knew this service from her” (Mrs. F1).

However, many of them experienced difficulty in accessing information on social services. Most carers in Seoul said that they searched for social services information by themselves. Moreover, hospitals and social service provisions do not connect automatically each other. Unlike Scotland, there is no system like regular district nurses visiting older people with dementia in Seoul. This makes it even more difficult to access information for older people with dementia and carers. Moreover, every district has slightly different information, thus, people were confused about service information.

“Many people in hospital worry about the time after discharge from hospital. However, hospitals do not say anything about services. Nurses have more experiences than us but they do not know about it. I saw many people (families of patients) in hospital worry and argue about caring after discharge because they do not know about home help services” (Mr. D1).

“Sometimes, I need home helper service urgently but couldn’t get it immediately. There is no information about it. I could not go out to search for the information to ask help. Doctors and social workers don’t share information and the information is very different from every Gu district in Korea” (Miss. I1).

Only 2 carers in Seoul said that they knew about the LTCI scheme through carer meetings, whilst 12 carers said that they did not know about LTCI, although it was implemented in 2008. They stated that they wanted to use the long-term care if it was introduced.

“I did not know about long-term care before the carers’ meeting. I heard it would be introduced in August next year (2008). I think it is too late for me, I need it right now” (Mrs. G1).

“I never heard of it but if they provide care services at home I would like to use it” (Mrs. K1).

In Suwon, people knew about the pilot project through leaflets or visiting social workers in LTCI. According to a social worker in LTCI, social workers should search for the clients who are older people and need care at the beginning of the pilot LTCI project. Therefore, many carers did not search for information by themselves in Suwon.

“I did not know about pilot scheme but my friends told me. They received leaflet of the services” (Mrs.N2).

“Ms. Seo, a social worker at LTCI, comes. I am very thankful for that” (Mrs.L2).

The lower income group usually have their needs assessed by a social worker in the council. However, one carer pointed out the bureaucratic social workers in the council.

“A social worker in the city council did nothing and just called me to pick up something. They never visited my mum to see her situation. They just make phone call a lot and do documentary work. They did not provide real help or information for us” (Mrs. N2).

In fact, a social worker in council covers several hundred people, thus, they normally work based on documentary work. The lack of social workers may result in problems of accessibility of information and the delivery of services. In order to improve the accessibility of services information and delivery services, the council should be concerned with reducing the number of clients per social worker.

Accordingly, this section explores the accessibility of information in Korea. Markle-Reid & Browne (2001) argued that a lack of information can be a barrier to use social services, especially for carers and older people with dementia, because of the low accessibility of information. In fact, carers in Seoul seemed to have more difficulty in getting information compared with carers in Suwon because of a different long-term care system. Carers in Seoul searched for information by themselves while carers in Suwon got information through social workers in LTCI if their older people with dementia were assessed and got a degree of LTC.

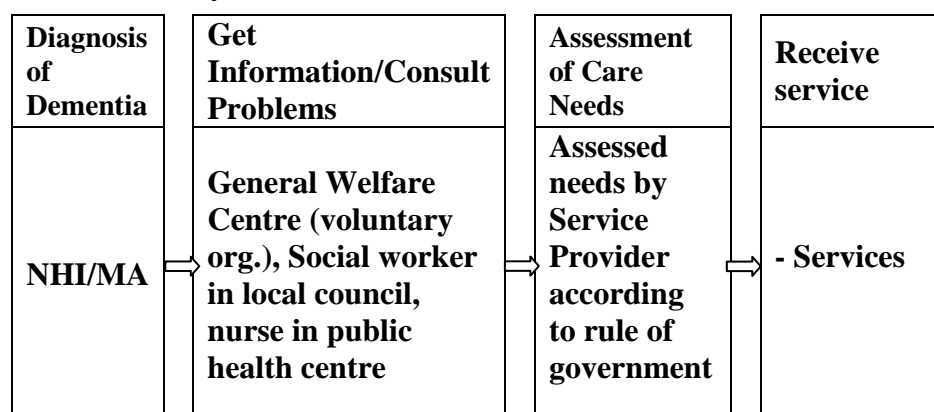
Process of Delivery of Community Services in Korea: Seoul and Suwon

The process of receiving community services is different in the two cities because Seoul did not have LTCI pilot scheme and Suwon had a pilot scheme and a different process to get services.

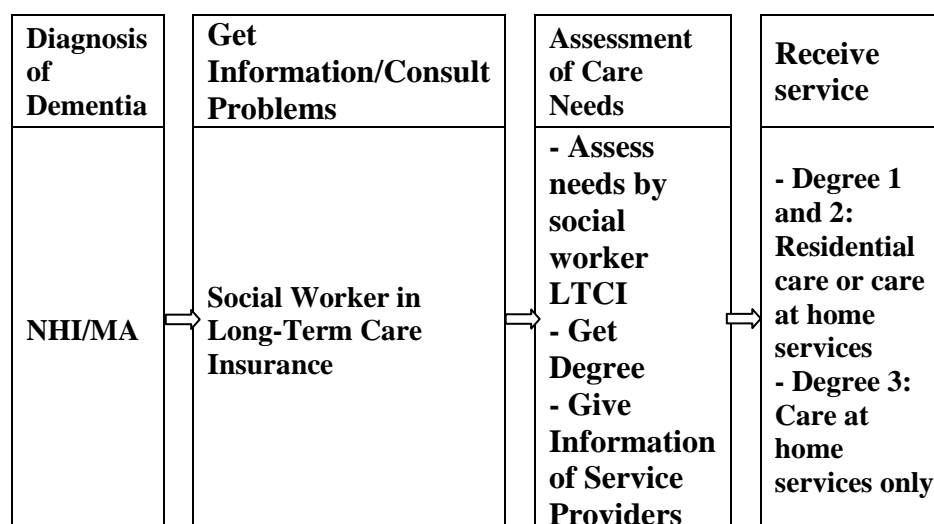
In Seoul, carers usually contacted the service providers directly and the social workers and service providers assessed the needs of older people with dementia in order for them to qualify to get government funds. Some in the lower income group contacted social workers in the local council or nurses in public health centres to get information on services. Then they referred to service providers and the service providers assessed their older people with dementia to provide services. In fact, most service providers in the community are voluntary organisations.

In Suwon, carers knew the pilot scheme through a publicity leaflet or by visiting social workers from the LTCI pilot project team. The social workers in LTCI assessed the needs of older people with dementia then gave information on service providers, and then carers chose one service provider to receive services from.

Figure 5- 2 Process of receiving community services in Korea
2007 Present System



Pilot Scheme of Long-Term Care Insurance



Service providers assess the needs of older people with dementia in Seoul, while social workers in LTCI assess the needs of older people with dementia in Suwon. The process of receiving services appeared to be simpler in Suwon than in Seoul. In Suwon, once older people with dementia get into the long-term care system they access services easily. However, older people with dementia and carers, whenever they needed a new service, had to have a new assessment and documentary work in Seoul. In fact, the pilot scheme improves

accessibility to services for the older people with dementia compared with the present system.

Community services at home in Korea: Seoul and Suwon

As mentioned above, LTCI was introduced in 2008. Suwon city had a pilot project of LTCI in 2007, while Seoul city has not provided a project of LTCI yet.

In Seoul, there were community services; respite care, day care and home help, especially domestic support, etc. In Suwon, they provided long-term care services such as home care services, especially personal services, day care, and respite care, etc. Although the contents of services are similar between Seoul and Suwon, the expense of the services is different between Seoul and Suwon. People in the lower income group in Seoul and Suwon received free services, while people in the higher income group were charged for the services, particularly people in the higher income group in Seoul who were charged the full payment, but people in Suwon were charged 20 or 15 per cent of the full payment.

There has been no general survey for the utilisation of community services among older people with dementia. However, Jeung and others (2005) showed that 0.2 per cent of older people aged 65 or over had experience using day care and 0.7 per cent of older people used domestic support. In the case of the dementia counselling

centre, the amount of people who had used it and were using it was 0.7 per cent and 1.0 per cent respectively. 2.7 per cent got meals on wheels service and 2.1 per cent received visiting nursing services. 1.9 per cent of people used the aid support service. It demonstrated that few people had experienced social services in the survey. The low utilisation of community services may result from a lack of services, affordability, accessibility and cultural reasons.

Seoul

For carers in Seoul, 9 out of 14 older people with dementia received community services while 5 older people with dementia did not receive any services. Two carers had attended carers' meetings. Two people received free continence pads once a month from a dementia centre. One carer had two private carers, one private domestic carer, and a personal carer. The other carer used private respite care. According to the table, higher income groups had fewer social services than lower income groups. All people in lower income groups received at least one service, while only two people in higher income groups received social services. There were no packages of care for older people with dementia in Seoul.

Table 5- 4 Receiving care services in Seoul

	Case	Social Service	Remark
H I	Mrs. A1	Nothing	
	Mr. B1	Nothing	Private personal carer, Private domestic carer
	Mr. C1	Nothing	
	Mr. D1	Visiting Nursing Care (Ministry of Labour Project, Creative Job), 2 hours for Mon- Fri day, charge for actual expense: £2.5 for an hour Total: £100 per month (£25 per a week x 4)	
	Mr. E1	Nothing	
	Mrs. F1	Short-term Care in General Welfare Centre, charge for actual expense: £250 per a month (30 days, excludes continence pads)	
	Mrs. G1	Nothing	Respite Care for two months in last summer: £1000 (£500) per month, Carer meeting
L I	Mrs. H1	Free Day care centre 9am-4:30pm on Mon-Fri. Bathing services in Day Care Centre: two times per month	
	Miss. I1	3 months respite care in hospital: co-payment of hospital charge £50 + caring fee £350 = £400 per month	Free Continence Pads 40 from Dementia Centre (funded by Seoul City and District) Free visiting nurse two times a week at home Carer meeting
	Mr. J1	Free home helper 10am-3pm, once a week	
	Mrs. K1	Free respite care	
	Mrs. L1	Free respite care	
	Mr. M1	Free respite care	
	Miss. N1	Free home helper 2pm-5pm, three times a week	Free continence pads, 40 from Dementia centre (funded by Seoul City and District)

In Seoul, only one older person with dementia used a daycare centre.

Mrs. H1's mother attended a daycare centre five days a week.

“My mum and aunt attended daycare centre. They go to daycare centre from Monday to Friday from 9 (am) to

4:30 (pm). ... Daycare centre also provides a bath service twice a month” (Mrs. H1).

Two carers used visiting nursing care services or home helper services at home. Mr. D1’s mother needed nursing care, thus Mr. D1 arranged a visiting nursing service. His mother received the service from Monday to Friday. He paid an actual service charge of about 25 pounds a week for the service which was provided by the voluntary sector. Miss. N1 received a free home helper service three times a week.

“Visiting nursing care is needed for my mum with dementia and cholelithiasi. Visiting nursing care service is not provided in many places. My mum is using it in two places two hours each in week” (Mr. D1).

“Home helper provides the service for domestic work three times in a week” (Miss. N1).

Five out of fourteen carers used respite care in Seoul. One carer in a higher income group paid an actual service charge for the respite care whilst three carers in a lower income group paid nothing for the service. Reasons for using respite care were relieving the caring burden, health problems and using alternative long-term residential care.

“My mum does not sleep in the night and gets up early. She disturbs others’ sleep. So my sister and sister’s husband could not sleep at night. Their health was getting worst so I suggested my sister use respite care” (Mrs. F1).

"I use respite care. I think this will protect to leave my aunt behind. There is no fee for the service" (Mrs. K1).

One carer used respite care in hospital for three months every summer since her mother got vascular dementia in 2002. There was a financial reason to use respite care in hospital although they were charged to use the hospital. If she uses respite care for her mother, the subsidy from the government goes directly to the respite care provider, except a hospital.

"I let her go to hospital for three months every summer. The service fee is a big burden. It reaches about 330 thousand won every month including personal care. (Why don't you use respite or long-term care service?) If we use them, state subsidiary is paid to providers of the services. This makes life of me and my nephew difficult. So we should use a hospital" (Miss. I1).

Except Miss I1, there were three carers in a lower income group who used respite care. All of them used a respite care service because there was a long waiting list for free residential care.

"After my father died, I cannot take care of my grandmother properly. So I sent her to respite care. I'm now searching for long-term care" (Mr. M1).

"My husband has a big fight with his mum every night because my mother in law doesn't sleep in a night. I'm so tired. ... We should wait for entrance of long-term care home. So we decide to send our mum to respite care home" (Mrs. L1).

Mrs. F1 also wanted to use long-term care for her mother but her mother was in respite care because the charge of residential care was more expensive than respite care.

“Long-term care home is truly very expensive. On average, 1 million won or 1.5 million. It’s too expensive to us. Our brothers are over 70 years old and it’s a big burden. The cost for respite care is just 100 thousands. So we are here” (Mrs. F1).

Accordingly, carers in lower income groups desperately needed proper care for their older people with dementia. Most carers in lower income groups have full time jobs but there were no packages of services to support carers and older people with dementia at home. Thus, they used respite care for their relatives with dementia. Moreover, they were keen to use residential care but there was not enough places for them, so they continued to use respite care.

Two carers had been to a carers’ meeting. The carers’ meeting provided knowledge of dementia and care from other carers.

“In the meetings(carers’ meeting), I have known what dementia is and how we care. Likewise, we can exchange information. In addition, we take comfort from sympathy together” (Miss. II).

The dementia centre provided free continence pads for those in lower income groups.

“Dementia centre provides 40 nappies and mat. Those are very helpful to us. The free nappies make me very happy and I am waiting for the provision” (Miss. I1).

There were two carers that used a private helper or respite care. One carer used a private personal helper and a domestic helper for his wife. Mr. B1 had a regular income of £3,500 per month, although he had already retired. He could afford to use two carers for his wife and domestic work. Mrs. G1’s carer used private respite care because she had pain in her arm in the summer of 2007. She used respite care for her father for two months.

“Since 2003, I have used helpers. Housework is conducted by a private personal helper and a domestic helper washes and cares for my wife when the private personal helper doesn’t come. The cost for these helpers is 2 million per month” (Mr. B1).

“The pain shoots up my arm in last summer. So I sent my dad to respite care for two months. ... The fee was one million and my brothers paid” (Mrs. G1).

The study shows that if carers and older people with dementia can afford it then they could use community services in the private sector, but most older people with dementia are not economically independent, thus they find it difficult to use private care services. In fact, only Mr. B1, who had a regular income and was economically independent from his family, used private home help for his wife. Public services are mainly for the lower income groups, thus it is also a barrier for the higher income groups.

Suwon

In Suwon, 9 out of 14 older people with dementia received community care services whilst 5 older people got no services. Two carers had been to a carers' meeting. There was one case in which a private domestic worker cared for the relative with dementia. Higher income groups get slightly less social services than lower income groups. Two carers in lower income groups didn't have any support from social services, whilst three carers in higher income groups received no social services. Most carers who received social services received day care or home care. However, they were not provided with a package of services like older people with dementia in Seoul.

Table 5- 5 Receiving care service in Suwon

	Case	Social Service	Remark
H I	Mrs. A2	Nothing	LTCI: 3 grade
	Mrs. B2	Nothing	LTCI: 3 grade
	Mrs. C2	Nothing	LTCI: 1 grade, Private service: Living with private domestic worker
	Mr. D2	Day care centre: 9 am-5 pm on Mon-Fri, total Fee: £75 per month	LTCI: 2 grade , carer meeting
	Mrs. E2	Home carer 4 hours per day three times a week Total Fee: £50.1 per month (£12.52 per week x 4)	LTCI: 2 grade, carer meeting
	Mr. F2	Home carer 4 hours a day, 8:30 am-12: 30pm on Mon – Sat. Total Fee: £ 83. 5 (£20.87 per week x 4)	LTCI: 2 grade
	Mrs. G2	Day care centre 8: 30 am-4 pm on Mon-Fri. Total Fee: £50 per month	LTCI: 3 grade
	Mr. H2	Free home carer 3-7 pm (4 hours a day) on Mon-Fri	LTCI: 2 grade
L I	Mrs. I2	Free home carer 10:30am-2:30pm (4 hours a day) on Mon-Fri	LTCI: 1 grade
	Mrs. J2	Nothing	LTCI: 3 grade Use to go to free day care centre 8:30am - 4pm on Mon to Fri.
	Mrs. K2	Free day care centre 9am-5pm Mon-Fri	LTCI: 3 grade
	Mrs. L2	Nothing	LTCI: 2 grade Rent protect mat for bed sore
	Mrs. M2	Free home carer 9am -1pm on Mon-Fri. Free Bathing Service once a Month. Free visiting nurse once a month from public health centre	LTCI: 1 grade Free continence pads from public heath centre, rent protect mat for bedsores
	Mrs. N2	Free home carer 2pm-6pm Mon-Fri. Free visiting nurse two times a month	LTCI: 1 grade Rent: Bed, Wheelchair, Shower chair from LTCI

3 out of 14 older people with dementia attended a daycare centre in Suwon. Two of them paid co-payments while one of them received it free because of a means-test.

“My mother goes to a programme run by a community centre from 9 to 5 in a week. She adopts herself into the programme despite a small problem” (Mr. D2).

“My husband uses a daycare centre from 9 to 5 in a week. During the time, I go to market and prepare for a meal” (Mrs. K2).

Markle-Reid and Browne (2001) pointed out that people with a high level of need may face important barriers to the utilisation of services because of ‘restrictive eligibility criteria or the lack of trained personnel’. In the case of dementia, patients have many more behavioural problems than people with a psychological disability. Therefore, Mrs. E2 experienced the barriers to use a daycare centre because of her mother-in-law’s behavioural problems.

“My mother-in-law didn’t fit in at the daycare centre. The centre refused to accept her. She thrust away, pinch and speak ill. Our mother-in-law ruins the atmosphere and cannot go to the centre” (Mrs. E2).

In a daycare centre, patients are divided into two groups: those who receive NBLS, and those in a higher income group. Those in lower income groups could feel a sense of alienation. It shows the residual welfare system affects the utilisation of community care services. In the case of Mrs. J2’s mother, she felt inferior in a daycare centre, thus, she stopped going to daycare.

“Last year my mum went to a day care centre. My mum was only a NBLHS recipient. Older people boastfully spoke about their children she might feel a sense of inferiority so she didn’t want to go there” (Mrs. J2).

6 out of 14 older people with dementia received home care services. Two carers used home care services in higher income groups while four carers got the services in lower income groups. The number of people in lower income groups doubled compared with higher income groups. It shows that affordability may be matter when using home care services. However, Mrs. E2 appreciated that LTCI reduced the economic burden of using services.

“My mother-in-law could get a care at home service for 4 hours per day for five days. It is total of 20 hours per a week. But she receives three days and a total of 12 hours of services. I appreciate the government that I can get the services. I pay for it, for 100,000 per month. I used to use private carer. I paid 540,000 per a month and gave extra 100,000 per a month. She came every day. It was very hard economically” (Mrs. E2).

Mr. D2’s mother received services for around four hours for 6 days. Mrs. M2 also used home care services four hours a day. Mrs. M2 lived with her mother in a rented room without a bathroom, thus her mother received mobile bathroom services. Moreover, Mrs. M2 and her mother depended on only the government benefit which is a very small amount, so they could not eat nutritionally. The helper from the bathroom services, from the voluntary sector, brought meat and Kimch (traditional dishes) every month.

“The helper comes at half past eight and goes at 1 o’clock from Monday to Saturday” (Mr. D2).

“I have received them from three years before. Helpers cared from 9 to 5 at first and now for four hours. They

help going to the bathroom and taking meals for my mum. In the case of bathing my mum, she receives once a month. In addition, they give Kimch and pork cooked” (Mrs. M2).

Mrs. N2 used home help services recently to fill the gap during her work. Her mother used to skip her meals because of the absence of a carer. She felt sorry but she needed to work to provide an income for her and her family. A situation without home help services results in the neglect of older people.

“I knew LTCI pilot project but I didn’t use it because I could do it. ... I gave a lecture for singing a song once a week. At that time, I could not give my mum a meal so she skipped a meal. I applied to home care services. These days, the services are conducted from 2 p.m. to 6 p.m.” (Mrs. N2).

Two carers had been to a carers’ meeting in the General Welfare Centre. They received knowledge on dementia in the meeting.

“I used to attend carers’ meetings several times. They are run by the General Welfare Centre. The information about dementia and caring is from the meeting” (Mr. D2).

One carer used a private home helper because her father-in-law needed 24 hour care. Moreover, she had a clothes shop business so she could not provide care all the time.

“We often keep vigil over a sick father-in-law. For taking a rest and working, we use a home helper and

*maid with 1 million and 300 thousands won per month”
(Mrs. C2).*

Mrs. C2 felt that a maximum of four hours a day of services at home was not enough to look after her father-in-law, thus, she used a co-resident private home helper. Actually, she was searching for a residential care place for her father-in-law because long-term insurance did not provide the care package that she needed.

In a few words, the participation in community care services was similar between Seoul and Suwon. However, higher income groups in Seoul had fewer services than higher income groups in Suwon. In general, higher income groups also got fewer services than lower income groups in both cities. This difference could be explained by the financial aspect and a lack of social services may influence the utilisation of social services among higher income groups.

Evaluation of community services in Korea: Seoul and Suwon

Seoul

Day care services benefit not only family carers but also community-residing older people with dementia (Gaugler *et al.*, 2003). There were positive attitudes towards day care services among carers. Mrs. H1 used day care for her mother during her work. She stated that she felt confidence about services. Moreover, carers were willing to use day

care although they did not use it. Mrs. A1 did not use day care but she thought it would benefit her mother.

“I really like my mum attends a programme of day care centre. She can learn something there. I am working so if my mum and aunt go there I’m very safe and comfortable” (Mrs. H1).

“My mum does nothing in home. So I would like my mum go to daycare centre” (Mrs. A1).

However, two carers complained about day care services because of the long-waiting time and accessibility of the services. It shows that a lack of services may result in the low utilisation of day care services in Seoul.

“It will be good for my mum to go daycare centre but there is long waiting list. I tried to call the programme organiser, organiser said I would wait for a long time” (Mr. E1).

“In the case of day centre for older people, they should be picked up by cars in front of house but they live in the hillside (in general, where many poorer people live) so the cars did not want to come to pick them up. ... But welfare centre (which usually provides social programmes for various people) choose people in good and clean villages. Alienated people still are alienated” (Mrs. H1).

Carers stated that they felt relief whenever a home helper or visiting nurse came for their relative with dementia.

"I feel relief when the visiting nurse comes. I want a nurse to come on weekend as well. When there is no service on the day, I feel very burdened" (Mr. D1).

"A visiting nurse makes me relax. I can use the time for myself and take a rest" (Mr. J1).

Nevertheless, one carer pointed out the problems of home help services, for example, a change of formal carers and a lack of services.

"I hope a carer doesn't change very often. Now the carer change once a month or two months so the adaptation takes a long time" (Miss. N1).

"If home helper comes to take care of my aunt, I will not send her to respite care" (Mrs. K1).

In the case of respite care, most carers got enough respite and were less stressed. However, there were complaints about the period of respite care because the older people with dementia could not stay in respite care over 3 to 6 months at one place. Many respite care users used respite care as an alternative to residential care, and thus, they felt the period of respite care at one place was too short.

"We are very fine because my mother-in-law is in respite care. Troubles in family disappear and we can go to work. That's very good. But what is bad is moving from one to other place whenever my mum adapts herself to new circumstances" (Mrs. L1).

"I feel relief after using respite care. ... In the beginning, my grandma moved respite care every three months according to the regulation. When she moved to other places, she needed her dementia diagnosis certificate, health certificate and NBLH certificate. I took my

grandma to get all the documents. It was so hard for me because I had job to do” (Mr. M1).

Carers pointed out the positive points of carers’ meetings and dementia centres. They received good information and it gave them new energy.

“Family carers’ meetings are good because we can get good information and share our experiences. We just talk to each other but it helps my problems. I realise that there are people in harder situation than me. I feel fortunate to look after my father” (Mrs. G1).

“I felt reliance upon the carers’ meetings because there were carers like me. They had similar problems as I had, so I felt comfort” (Miss. I1).

Two carers used private services in Seoul. They explained the benefit of private services. Mr. B1 said that private helpers are an alternative to residential care. Mrs. G1 gets a break due to her use of private respite care.

“Private services are better than residential care. If my wife is in residential care home, I just go there very rarely. But now, I can see my wife anytime and my life is not interrupted by her. This is thanks to home helpers and a maid. The expense of residential home may be paid around two millions won. Private services’ fee is similar. I prefer that kind of care” (Mr. B1).

“My arms were so paining in this summer so I used private respite care for my father. After he came from (private) respite care, I felt that I should give him better care. I felt refreshed and energetic not only physically but also psychologically. If I feel it is hard to care for him then I would like to use (private) respite care for a month” (Mrs. G1).

Accordingly, carers had positive attitudes towards community care but carers commonly pointed out a lack of services. They wanted to use the services but the low accessibility affected the low utilisation of daycare and home help services. Moreover, they were very keen on using services. It shows there are no strong negative attitudes based on culture.

Suwon

Users of day care felt relief during the services time and they did other social activities during the time. Mr. D2 stated that his social activities shrunk due to caring for his mother but the daycare supported him in having a social life.

“There is no social life after caring for my mum that is the hardest thing. After using the daycare centre, it is getting better, because I can do something during that time” (Mr. D2).

However, there were issues about fees and a lack of professionalism. As mentioned, LTCI does not fully cover the fee at the point of using services. Mr. D2 felt there had been no change in the charging, although the long-term care pilot scheme had been introduced. Mr. F2 pointed out that daycare was not specified for older people with dementia. Therefore, older people with dementia are denied by a social worker as a service provider. Moreover, carers expected

professional treatment or a programme of daycare for dementia. However, the programme was not focused on older people with dementia.

“Daycare centre fee was 12-140,000 won per month including meals before long-term care pilot scheme, after we pay 150,000 per month include meals. It is 15 per cent of total fee. ... There is not change of fee. Church organises this programme so they receive small amount of money for daycare centre before the scheme” (Mr. D2).

“Daycare centres do not provide professional programme for dementia. And day care centres do not accept older people with memory problem. There is lack of programmes for older people with dementia” (Mr. F2).

It demonstrates a lack of service provisions for older people with dementia. Moreover, older people with dementia are the least favourite for service providers. In fact, some social workers mentioned that they needed more money to care for older people with dementia because of problematic behaviour which requires more staff, but the LTCI pays the same amount of money to service providers without consideration of the difficulty in caring for dementia sufferers. This resulted in denial of services to older people with dementia. However, LTCI has the intention of providing care and emphasising care for older people with dementia, but this intention does not work in reality. The government should consider the discrimination of older people with dementia and promote dementia-specific daycare centres and programmes.

Carers generally had positive attitudes towards home helper services. They felt less burdened and relief. They did relax during the services. Carers do various things; sleep, shopping, working during the time. Moreover, the services helped reduce their worry and strain brought on by caring.

“Because of home helper services, I can sleep or go to market. Likewise, the services make me refresh and so I can take care of my mum with a fresh mind. If there is home helper, I think caring at home is better than residential care” (Mrs. E2).

“In the past, I was worrying about my aunt when I go to work. The services make me very relaxed and comfortable” (Mr. H2).

There were issues regarding a change of staff and lack of services, although they appreciated home helper services. Mrs. M2 highlighted the problematic change formal carers regularly. She said her mother got confused whenever the formal carers changed.

“I am very satisfied after LTCI pilot project. Who looks after sufferers very well likewise? Many thanks. ... I want the home helpers are not changed because sufferers are confused. Now the helpers get changed every six or ten months” (Mrs. M2).

Mrs. I2 thought the four hours services was not enough because she had to work. Mrs. N2 wanted to use home helper services during weekend for her mother because she worked during the weekend.

“I really want to have service for all day. They do it for just four hours. It is not enough because I should do work for my family” (Mrs. I2).

“I need care for my mum on the weekend because of my job (singer). Sometime I go to another city to sing. I just leave her alone so I worry and get stress” (Mrs. N2).

Accordingly, some carers who had a full time job or part time job really wanted a package of care to maintain their occupation. However, the long-term care pilot scheme did not provide packages of services. In this situation, it is hard to continue a job whilst caring, thus, early institutionalisation is expected.

Mr. F2 highlighted the lack of professionalism of home helpers. He thought the formal carers did not provide a special programme for older people with dementia. Moreover, he expected comprehensive services from formal carers but it did not happen.

“LTCI is in the early stage so that carers are not professionally educated, home helper and nursing assistance. The formal carer (helper) comes and kills time. For four hours, she does nothing but watching TV with my mum. ... They do not provide professional programme for older people with dementia. But it is better than nothing. ... But it is waste of government budget” (Mr. F2).

Home helpers should be trained and educated about older people with dementia and provide services according to needs of carers and older people with dementia. Moreover, carers do not have clear information on what services they provide. Thus, social workers in LTCI and

service providers should inform their clients on what services they could receive or not.

Moreover, there was an issue about formal carers' health and strength. In the case of the home helper service, only one formal carer visited and provided help with daily life. However, there were four older people with a bedridden condition in Suwon. One formal carer makes it difficult to provide proper services for them because disability of older people with dementia. Furthermore, most houses where older people with dementia stay do not have special facilities for bedridden people; for example, a hoist for get up and to go to bed. Therefore, most older people with a bedridden condition stay in bed all the time. Older people with a bedridden condition look at the ceiling all the time and their bones and muscle become weak and rigid.

One formal carer visit and a lack of mechanical aids caused risks not only for older people with dementia but also for formal carers' health. Moreover, bedridden older people seem have their well-being neglected. In Scotland, two carers visited an older person with dementia for personal care and there was a hoist or other aid facility if older people needed it. Therefore, Scottish older people and formal carers are less hazardous compared with their Korean counterparts. The Korean long-term care system should investigate and improve the work and care environment.

There were positive and negative points regarding family carers' meetings. Most family carers' meetings seemed to provide a

lecture on caring for dementia sufferers. Some carers said that the knowledge of coping with dementia in the meetings was useful for the early stages of dementia, but that it did not reflect reality well.

“I know the information of dementia in the meeting of family with dementia. However, now the information is not useful because it is related to information about initial stage of dementia” (Mr. D2).

“Carers programme helps to understand dementia but theory is different from real situation. There are many unexpected situation to care for older people with dementia” (Mrs. E2).

In Suwon, most carers appreciated the fact that their city provided a pilot scheme of LTCI. They felt proud that their city provided the long-term care pilot scheme.

“Through the LTCI, I become to trust the government and thank for the wonderful benefits” (Mrs. E2)

“Thankfully my city provides pilot scheme so home carers come to help us three years ago. ... She (formal carer) helps my mum’s toileting and eating. I can go somewhere without worry about her” (Mrs. M2).

Mrs. C2 and Mrs. L2 do not use services but they appreciate the pilot scheme.

“I don’t know about LTCI well. My neighbour uses the services. She said it is very good. Her mother-in-law used to be hard faced but she is delighted at the home carer. So I think they do well” (Mrs. C2).

“I was very surprised about LTCL. I am very thankful to the pilot scheme and think the government do really big event. I am very appreciative that the government provide these social welfare” (Mrs. L2).

There were issues surrounding the long-term care service fee because most older people with dementia were not financially independent. Older people with dementia in higher income groups in Suwon have to pay the co-payment of the services charges. It creates a barrier for the older people, especially older couples dependent on their adult children. Mrs. A2’s daughter said that her mother did not want to use services for her father because she did not like a stranger visiting their house. However, when the daughter went out, Mrs. A2 didn’t agree. She said that it was difficult to care so she wanted to use the service but she did not want be a burden to her daughter. Mrs. L2 also said her neighbour needed care but the co-payment discouraged her utilisation of the services. Older people in this study mainly depended on their family income, thus, using services was a burden for family. Therefore, older people did not use services although they wanted to use them.

“If it is free, I really wanted to use it because I am in a corner. But I could not tell my daughter to pay for it. I know her situation well. How I could tell her it again and again?!” (Mrs. A2).

“My neighbour is a blind lady. She needs help but she should pay for services. She said that she does not want to receive service. She really needs it but she does not have any money to pay for the services” (Mrs. L2).

Mrs. B2 also did not use services because of the payment at the point of use. She mentioned that the pilot scheme did not give any benefits for family carers who did not use services. She thought there should be a reward for carers that care for their relatives with dementia without using services, although they are entitled to use the services. In the same vein, Mr. D2 argued that LTCI should provide a carers' allowance.

"If we use the care at home services, we should pay 15 per cent of the total fee. I would not want to pay for it so I do it myself. But there is nothing for carers even though I take care him on my own. If somebody looks after their older people with long-term care, government should give medicine fee (small amount) for carers. It is not fair that they do not have any benefit" (Mrs. B2).

"They should give allowance for family who look after their older people with dementia for long time without services, especially residential services" (Mr. D2).

Mrs. K2 complained about underestimate of long-term care degree because dementia person looked likely physically healthy and normal, although he has cognitive problems. In fact, the manual of assessment of LTCI shows that ADL due to physical disability gains higher points than consciousness problems.

"Social worker K came and assessed my husband needs. Whenever she comes, he acts like a normal person. So I asked her favour and said to her. He was very bad when I am with him. So he get third grade to get services" (Mrs. K2).

The evaluation of services is fairly similar between Seoul and Suwon. Generally, carers were satisfied with the social services and they felt less of a burden and relief after using services or attending carers' meetings. Moreover, carers in Suwon seemed very proud of their city for providing the pilot scheme. However, there are problems related with services such as long waiting lists, the changing of helpers, the burden of service fees, discrimination and difficult accessibility, etc.

This section demonstrates community care at home in Korea. There are similarities and differences in community care at home between Seoul city and Suwon city. As mentioned above, Suwon city had provided a pilot LTCI scheme while Seoul city had not in 2007. Therefore, it was expected that carers and older people with dementia in Suwon would get information more easily than their counterparts in Seoul. Regarding the process, the process of receiving services in Seoul is more complicated than the process in Suwon. Moreover, people in Suwon have more community service involvement than people in Seoul. Thirdly, carers in Suwon had more positive attitudes towards community services than carers in Seoul.

5.4 Summary

Community care has been examined in Scotland and Korea in this chapter. There are similarities between the two countries but the differences are found in this examination. In addition, the causes can be found in the social welfare systems rather than their cultures. This is because the community care in Korea is close to a type of residual social welfare, whereas in Scotland it is similar to a type of institutional social welfare. Therefore, the differences between the two countries will be discussed from the point of view of institutional difference as below.

With regard to the acquisition of information, carers in Scotland seemed to be able to access information on services more easily than carers in Korea. Scottish older people with dementia have regular visits from district nurses after a diagnosis of dementia. Yet, the majority of Korean carers in Seoul searched for information by themselves. On the other hand, carers in Suwon seemed to have easier access to service information than those in Seoul, because social workers in LTCI provided the information after an assessment of needs. None the less, only a few people knew about services information, even in Suwon.

Older people and carers in Scotland have more community care than in Korea. Scottish older people with dementia get packages of care services like free personal care at home and daycare. In contrast, Korean older people with dementia tended to receive very limited services. Previous studies explained that the low utilisation of community care services in Korea is attributed to culture. However, this study discovers that it is because of institutional factors. As can be seen in the Suwon cases, the Korean carers were eager to use community care services if the services do not cost too much for them. In addition, it has been proved that a lack of services leads to the low consumption of services in Korea. Likewise, the accessibility and affordability of community care results in carers' attitudes towards the utilisation of services.

In the future, accessibility will be improved. The LTCI will increase the service supply. For example, the number of day care centres and users rose rapidly from 2005 to 2006(see table 5-6). It also shows the number of day care centre and users in Kyung gi province, which includes Suwon city, increases dramatically. It means that the pilot scheme influences the growth of day care services. However, there is shortage of services for older people with dementia as seen above. There was strong discrimination for older people with dementia in the day care services. In fact, day care centres in Korea were not specified for older people with dementia. Moreover, older people with dementia need professional care. Therefore, Korean

government should be concerned to encourage day care centre for older people with dementia.

Table 5- 6 Number of day care centre and users in Korea

Year	Total		Seoul city		Kyung gi province (include Suwon city)	
	Day care centre	The number of older people who use day care centre	Day care centre	The number of older people who use day care centre	Day care centre	The number of older people who use day care centre
2005	280	4,378	67	1,137	54	838
2006	409	5,824	80	1,353	94	1,330

Source: MHWFA, statistic of social welfare for older people, 2007

In the case of the evaluation of services, there are also differences in Scotland and Korea. First of all, Korean carers complain about service fees and the professionalism of formal carers. Community services in Korea are based on co-payments. This is a barrier to the use of community care because older people with dementia are not economically independent, as mentioned above. Although the payment in LTCI is less, there are still service charges. In addition, there is an issue about the professionalism of the home-helper service in Korea. The home-helper services seem not to have special programmes for older people with dementia. Thus, carers tend to complain about a lack of professionalism of formal carers. On the contrary, Scotland has developed a home-helper service, and therefore, there are more efficient programmes. As can be seen above, there

have been issues about a lack of aid facilities, and the limit of one formal carer per visit in Korea in contrast to Scotland.

In brief, the cultural aspect should be reconsidered in explaining the effect on carers' attitudes toward the utilisation of community care services. This is because differences in accessibility and the affordability of information and services make a significant difference regarding attitudes.

Chapter 6. Carers' Attitudes towards Residential Care in Scotland and Korea

Previously, this study examined the attitudes towards community care. This chapter explores family carers' attitudes towards residential care³⁴ in Scotland and Korea. These attitudes will be different under each culture and each social policy.

The preference for residential care has been explained by cultural variation in much literature, especially Asian studies. For example, previous studies have explained that Korea has a strong familialism based on Confucianism, which assumes that adult children should care for their parents (Kim, 2001). Kim (2001) points out that 'the traditional social norms and characteristics of family-centred care-giving are still deeply rooted in Korean society despite (the fact that) traditional familial obligations are changing'. Accordingly, Koreans attach a strong stigma to residential care, and thus have strong negative attitudes towards it.

On the other hand, Esping-Andersen (1999) said that 'defamilialized' and 'de-commodified' care is reflected differently in different welfare states. Korean social policy for older people

³⁴ I focus on residential care which includes residential care home and nursing care home but not long-term care insurance. In Scotland, long-term care hospital is free and covered by NHS. In Korea, long-term care hospital is not free and covered by NHI. Older people with dementia in long-term care hospital in Korea cannot benefit from long-term care insurance. Therefore, long-term care hospital exclude in this survey.

developed under the slogan ‘family first and state later’. In other words, social policy in Korea has been developed based on strong familialisation. Moreover, the welfare system in Korea is recognised as being a residual system. Entitlement was based on a strict means-test and was only available for public sector residential care until 1993³⁵. Therefore, Korean carers are less in favour of using residential care compared to carers in Scotland.

This chapter aims to explore attitudes towards residential care in Scotland and Korea and identify the origin of those attitudes. Firstly, it examines what carers’ attitudes are towards residential care in Scotland. Then, it investigates Korean carers’ attitudes. These two sections demonstrate how a different culture and social policy influences carers’ attitudes towards residential care. In detail, they will answer the following questions: Do carers want to use residential care? When do carers recognise the need to use residential care? What are the factors affecting carers’ willingness or unwillingness to use residential care in Scotland and Korea?

³⁵ The law of older people’s welfare, including permission for private residential care was leistered on 30th November 1993 (Lee et al., 1994:305). Therefore, this welfare was only available for public residential care homes, which, until 1993, older people would only be entitled to through undergoing a means-test.

6.1 Carers' Attitudes towards Residential Care in Scotland

Attitudes towards residential care in Scotland

According to Alzheimer Scotland (2007), 40 per cent of older people with dementia live in residential care or hospitals, whilst 60 per cent live in the community. In this study, none of them, at present, want to use residential care. However, 7 out of 14 people are willing to use residential care in the future, comprising 3 spouses and 4 children. All 4 children lived apart from their parents with dementia. On the other hand, 7 out of 14 Scottish carers, comprising 4 children and 3 spouses, are unwilling to use residential care in the future. There was no significant difference of preference towards residential care between income groups, however, 4 carers in the lower income group are willing to utilise residential care, whilst 3 carers in the higher income group wanted to use it in the future.

Table 6- 1Attitudes towards utilisation of residential care in Scotland

	Case	Present	Future
HI	Mrs. A	No	No
	Mrs. B	No	Yes
	Miss. C	No	No
	Mr. D	No	No
	Mr. E	No	Yes
	Mrs. F	No	Yes
	Mr. G	No	No
LI	Mr. H	No	No
	Mr. I	No	Yes
	Mr. J	No	No
	Mrs. K	No	Yes
	Mrs. L	No	Yes
	Mrs. M	No	Yes
	Mrs. N	No	No

Residential care, whether the carers were willing or unwilling to use it, was suggested by professionals, friends and colleagues in Scotland. Mrs. M's colleague had been recommended her to use residential care and Mr. E's doctor had suggested residential care for his mother. Mr. D's father had moved into a care home because his sister had arranged this while he was away. After he found out where his father was, he brought him back home.

"I never arranged for him to go into a care home. I never arranged it with the social worker. While I was away, my sister got him a place. I found him in a nursing home. He was petrified. ... I told them I had come to take my father home" (Mr. D).

Willingness to use residential care

Scottish carers did not accept the suggestion for residential care at present, although it had been recommended for their relatives. There were various reasons for this. For example, Mrs. M stated that she was concerned about her mother's opinion and Mr. E said that his mother is a very independent person. As a result, they refused to use residential care at present.

"When my mum was being a bit difficult about things, this man at work said to me, 'Oh, you should put your mum in a home, it's time for her to go into a home. ...'. I said 'She doesn't want to go into a home.' He said, 'It doesn't matter, it will make your life a lot easier if she was in a home'. That's what he did with his father. I said, 'I would only do that if she really wasn't able to cope at home'. " (Mrs. M).

"When she came out of hospital after a fall, it was a real struggle for the first week until social services stepped in. At that point, the doctor even asked me if I'd ever thought about residential care. Mum is independent. She would much rather be in her own place" (Mr. E).

Mrs. K stated that residential care could affect her mother's dementia because of a change of environment. Therefore, she wanted to keep her mother at home for as long as possible.

"I would rather she stays in her own house. My granny went into residential care, which was a good thing, but her dementia worsened much quicker. That was worrying for me. It wouldn't help my mum at all. I would be quite happy if it was to do with her physical health, but dementia is mental health, so I don't have any hesitation, you know, about putting her in a home" (Mrs. K).

Moreover, carers, especially those who lived apart from their relatives and receive care packages, are denied residential care at present. They said that if there were no services available, they would have put their relatives into residential care much sooner. This shows that community care is an important factor in delaying entry to residential care. Mr. E said that free personal care made a 'huge difference' to his decision to keep his mother in her own home.

"At some point, we will talk about it (residential care) if necessary. We never ever talk about it (residential care) now. We do cope by using the services she receives at the moment. (If we didn't have any personal care) I don't know how we would manage... I have fewer burdens and worry less now. Without it (free personal care), I would have done something by now... It (free personal care) made a huge, huge difference" (Mr. E).

Accordingly, these Scottish carers are not willing to use residential care at present. Firstly, they think their older relatives with dementia are not at the stage of needing residential care. Secondly, they are concerned about their relatives' opinion and the characteristics of dementia. Thirdly, they think they can cope at home with community care support. However, carers have different attitudes towards using residential care in the future.

All Scottish carers state that they do not want to utilise residential care at present. Nonetheless, they mentioned the time when it might be necessary for their relative with dementia to go into a nursing home. They wanted to use residential care when they could no

longer cope with caring for their relative with dementia, or if their condition worsened. Otherwise, they wanted to keep their relatives at home for as long as possible. Mrs. B could imagine that she would use residential care when her husband's dementia got worse.

"I wouldn't like him to go into residential care. I don't think he would like it. I know it is difficult because his mind has obviously changed. I think I could accept it more easily if he got to the stage that he was so bad that he didn't know where he was. But at the stage he is now, I wouldn't like him to go into residential care" (Mrs. B).

Mrs. F expected that continuing to care for her husband would become more difficult because of her own age and strength. Moreover, she had observed her friend caring for her husband who had incontinence. Therefore, she agreed to use residential care when she could no longer cope with caring for her husband.

"I thought about it (residential care). It could only happen if I just couldn't cope. If he becomes incontinent. It's only then, and not before. This (dementia) is an illness just like anything else, isn't it? As you get older, it is not as easy to look after someone who is incontinent. It is impossible for a husband or wife to look after them. I have a friend who has a really tough time. She said that she has to change his bed 4 times a day. He should be put into residential care. As you get older, you are not as strong so you should consider it" (Mrs. F).

Accordingly, spouse carers were worried about their capability of continuing with their caring role in the future, and as a result, they were willing to use residential care.

In the case of adult children carers, they also asserted that when their relatives need intensive care, they would like to use residential care. All four adult children who agreed with using residential care lived apart from their relatives and three have a full- or part-time job. Therefore, they could not provide proper care if their relative with dementia needed it 24-7. Carers said that they are willing to use residential care in the future.

“For as long as they (family) are able, they should look after their relatives with dementia, but I don’t expect mum to live with us... If she needs 24-7 care I certainly see some form of care home” (Mr. E).

“(If her condition got worse) I would consider it (residential care). If she was unable to make decisions for herself or she really wasn’t safe on her own, then she would have to go into residential care to be properly looked after” (Mrs. M).

Nevertheless, adult children carers had a strong willingness to keep their parents with dementia in their own home for as long as they could care for them. In fact, Mr. E and Mrs. K provided care for their mother regularly. In the case of Mr. E, he called his mother every day and took her to his house every weekend. In the case of Mrs. K, she was a full time carer for her mother. She visited her everyday and prepared meals for her. However, Mr.E and Mrs. K do not want to bring their parents into their own house to stay permanently because they were concerned about their other family members, for example the carer’s wife and their children, and mentioned the distress of living

with older people with dementia all the time. Therefore, they would finally choose residential care when they could not manage to care for their relatives themselves. Mr. E and Mrs. K explained:

“I wouldn’t go to extent of having mum live with us because I think the impact on the family would be... we wouldn’t enough space for her anyway... Currently, there I no problem with her coming to stay with us for a few days ... but I certainly wouldn’t look at that as a long-term solution” (Mr. E).

“My granny (with dementia) used to go out on the street at night-time. That’s a bit dangerous nowadays. If she is doing things like that and living here, I wouldn’t be able to cope. It is too much to live with a relative who has dementia all the time” (Mrs. K).

Accordingly, carers who would be willing to use residential care in the future stated their limitations when caring due to old age, lack of strength or having to balance work with their own family, when older people with dementia get worse.

However, they have a strong dilemma. For example, carers choose residential care when their relative gets worse or when they can no longer cope, but they are afraid of the guilt they will feel by doing this. Mr. E pointed out that guilt came from family obligation and media broadcasting about the poor quality of residential care.

“I would feel guilty if we put her in a home as it would be like we couldn’t be bothered to look after her, although we do quite a bit for her. I am able to look after her, so why shouldn’t I? But it comes to the point when we can’t do it any more. You hear stories on TV documentaries about people not being well looked after

in care homes. You'd just feel so guilty about that if you put her into a home... In my view, a hospital and residential care are totally different concepts. (Hospital is for someone who is ill and needs treatment?) Yes, absolutely. Residential care means that your family has stopped looking after you" (Mr. E).

Many carers suffer with guilt when they decide to use residential care. The relevant professional, such as a GP, nurse or social worker, and other family members should help the carer deal with the emotional distress and encourage their decision. Moreover, if the media provided positive information about residential care, this would help to reduce carers' feelings of guilt.

On the other hand, people who are willing to use residential care have made a positive evaluation of the quality of service. Some carers thought that residential care would be a good idea, mainly because older people with dementia would receive better care and would have company in the care home.

"It is (residential care) actually better for her" (Mr. E).

"I think it is good for her because she could talk to people and live a better life. She may feel very lonely at home" (Mrs. M).

This study investigated their attitudes towards quality of service. All seven carers in this group who were willing to use residential care evaluated residential care services as good (3) or fairly good (4). Mrs. F used to think residential care had a low quality of service, but she

changed her opinion when she visited J Residential Home, where Mrs. M also observed good residential care.

“I have only seen one place, which was J. It was really great, and fairly new. I always think residential care just setting there. But I think that is changing now. I thought J was brilliant. It is open-plan and each resident has his or her own room and en suite. It seems brilliant up there” (Mrs. F).

“Some of them are very nice. I think the staffs are kind. People are the most important thing. Obviously, you want it to be clean, not smelly, but I think if you’ve got good people working there, that wouldn’t happen. ... I went to a residential home that was fine. Clean, nice people, residents were happy and spoke about residents’ interaction with each other...” (Mrs. M).

Accordingly, carers are concerned about quality of service, such as a clean and nice environment, friendly staff and a private room, etc., as seen in the interviews with Mrs. F and Mrs. M. Distance is also an important factor to consider when choosing good residential care for their relatives. Using residential care does not mean ending the participation of a family carer. They are still willing to visit and be involved in the care, even though their relatives are in a residential care home.

“I prefer local residential care. There is a home at the end of that road. It would be very handy” (Mrs. K).

“When she gets worse, I will bring her here (residential care near Mrs. L’s home)” (Mrs. L).

Social stigma towards residential care could discourage carers' willingness to use it. All carers said there was no stigma attached to residential care or its users any more. Mrs. K asserted that there is no stigma attached to residential care, but dementia could be made worse due to the change in environment. Thus, she refused to use residential care at present.

"No I don't attach stigma to residential care. People have to use care homes. I don't think they have a stigma attached to them" (Mrs. L).

"(Is there a stigma attached to residential care?) No, years ago, residential care wasn't as good as it is now. K house, poor people went there for residential care but that was going back to 1930s. Now, I would feel happy if my mum went into residential care if she had physical problems but was mentally able. ... But she has Alzheimers. She would just sit in a corner. It wouldn't help her at all" (Mrs. K).

Another factor that discourages carers from using residential care is affordability. Most carers complain about the price of residential care, especially private residential care home fees. In Scotland, there is a hotel charge in residential care, although personal and nursing care is provided free of charge. Mrs. B complained about the expensive hotel charges of private residential care.

"I think it (residential care) is very expensive. That is awful. Your money would be gone in a short time... I honestly don't know how the nursing home can justify such charges. I don't think it matters even if you had the most luxurious accommodation. You don't pay the fees of a five-star hotel when you stay in a one-star" (Mrs. B).

According to one residential care provider, they raised the hotel charge because the payment received from the government for free personal and nursing care is not enough to meet the standard of quality services that the government requires. Therefore, they increase the hotel charge in residential care to maintain their business. Recent Care Standards require there to be a single room with a shower or bath for residents in residential care, and a higher number of staff. Therefore, many residential care homes have been required to be renovated to meet this quality standard. This rise in expenses has resulted in higher hotel charges in residential care. The government should not only investigate the quality of service but also support residential care to meet the required standard.

Moreover, carers are very against the 'sell house' policy. They feel that residential care should be provided by the state because they pay tax or national insurance. Moreover, they think they should have free residential care because of the NHS. Therefore, they are very against selling their house.

"It is my home. I am very much against it (sale of house to have residential care). My husband and I have worked hard all our lives. ... Why should they take our house? We were told that they (state) would look after us, from the cradle to the grave, they were the words they used. The state should pay for it (residential care). The state promised us and we have paid national insurance over the years" (Mrs. F).

“She gets her own house. But nobody in the family would expect that when mum dies. If mum needs to be in residential care, there is absolutely no hesitation about selling her house. My grandmother stayed in residential care (in hospital) for 12 years and there was no question about funding that back in those days. It was just provided” (Mr. E).

Mrs. K’s father is concerned about the sell house policy, and thus he bought the house where his wife lives now in his children’s names.

“Years ago, my dad bought the house (where my mother stays). He bought it in our (brother and carer’s) name. ... She would have Local Authority help. That’s why my dad did what he did with the house, because if the house was still on my mum’s name then the Local Authority would sell the house to help with residential care. I don’t think it (sell house policy) is very fair. Some people pay but some people don’t. As far as their savings are concerned, I don’t think they should take people’s savings ... why should one person save and another person not, but the person who has have to pay more. I think some income such as a pension should go towards care. The mean-test should be on income rather on savings” (Mrs. K).

Scottish carers are very conscious of social welfare as a social right. What is more, in the past they experienced long-term care in hospital. Consequently, they believe that residential care should be provided for free. The long-term care system in Scotland makes carers angry about the sell house policy and residential care fees, and the accessibility and affordability of residential care. This may result in a delay in entering residential care, which could cause distress for carers and neglect of older people with dementia, due to the burden of caring.

In summary, in my sample all Scottish carers denied using residential care at present. Nevertheless, carers would use residential care in the future because of difficulties in coping with caring and working at the same time, and because it would provide better care. They pointed out that they want to use residential care, but only when they can no longer cope well at home. Otherwise, they will keep their relatives living in the community for as long as possible. Moreover, they said they were coping well because of the provision of community care services. Although they would use care homes in the future, they would feel guilty about doing so. Four adult children, who lived apart from their parents, would choose residential care for their parents if their condition got worse, because they could not cope with caring for them and working at the same time. Moreover, they were concerned about their own family's well-being and, as a result, would not bring their parents into their own home. Carers tended to have made a good evaluation of residential care. All felt that residential care services were good or fairly good. In the case of stigma, carers in this group thought that nowadays, no stigma was attached to residential care or its users. In the case of expensive residential care and the sell house policy, they were very against both. They argued that they used to receive free care from the NHS and questioned why their relatives could not receive free residential care. They felt a right to have free residential care because they, and their relatives, paid tax and national insurance contributions.

Unwillingness to use residential care in the future

Seven out of fourteen carers would not want to use residential care in the future. Some mentioned that they did not even want to think about using residential care.

“I don’t want to put her in a nursing home. I don’t even want to think about it. It would happen over my dead body. No way” (Mr. H).

“I would rather have a house here adapted for her. I would rather take her into my home and see what I can do here” (Mrs. N).

The reasons for not wanting to use residential care are that carers mentioned older person with dementia would not like to go to into a care home. Mrs. A said her mother does not want to and, moreover, she has a very strong willingness to continue caring for her mother at home.

“He has never wanted to go into a nursing home and still doesn’t want to now” (Mr. D).

“At the beginning, when she was diagnosed with dementia, she asked me to look after her and not put her in a care home... She needs me and is always looking for me. She depends on me. When carers are here, she asks where I am. We have a very, very close relationship. All my life, I’ve been very close to my mum” (Mrs. A).

Mrs. A said that she has a special relationship with her mother and this affects her decision not to use residential care. Moreover, she would feel guilty about leaving her.

“My granny was horrible to my mum. She wasn’t a good mum to my mum. That is why my mum found it easy to decide put her into care. But I am different. ... It is my choice... My son and daughter told me to put granny in care. They don’t understand, but when they get to my age they will. I couldn’t leave her. I would find it hard to let her go somewhere else” (Mrs. A).

Accordingly, she has various reasons for refusing to use residential care, such as negative relatives’ attitude towards the care, willingness to provide care at home, feelings of guilt about using residential care, etc.

Mr. D mentioned that he has a sense of reciprocity, which is his motivation for looking after his father with dementia.

“It’s a personal thing looking after him, because I love him and how I was brought up. They gave us life” (Mr. D).

Other carers said there was no need for elderly people with dementia to enter residential care because they could be looked after by family members or could move in with relatives.

“I have thought about giving up my work and going back home to look after my mum full time. I would consider doing that if I had to. But we want to keep her in her own home right to the end” (Miss. C).

The carers who were unwilling to use residential care seem to have a strong willingness to continue to care for their relatives at home.

However, carers expect to receive more home help services in order to enable their relatives to stay at home. Mr. D thought he could manage to care for his father with the help of a care package and respite care.

“I would like to receive more respite care as time goes on. I will continue to look after him with the care package. I would say it is better for him to be at home anyway” (Mr. D).

As in Mr. D’s case, community care is important to keeping older people with dementia at home.

It is important to investigate carers’ evaluation of the quality of services, as this significantly affects their willingness to use residential care. Three carers said the quality of residential care services is good (2) or fairly good (1). Mr. G thinks residential care services are good because of his sister’s experience.

“I think they (care homes) are very good. My sister has Down’s Syndrome. She needs care all the time. She is coming up to 74. It was my choice to put my sister in a home. At the end of the day, they are all very nice. The care they provide is excellent. I would say that 90% of care homes are excellent but you do hear about some bad ones... The government tries to monitor that (care services), to try to make homes of a good standard” (Mr. G).

Miss. C said that the reason she does not want to use residential care is not because of the quality of care but her strong willingness to keep her mother at home.

“Some care homes are excellent, they are very good. But you hear about some that are not so good. It does make you anxious. I have mixed feelings about it. But it is not because I am anti-care homes. We decided to keep my mum at home because we always try to look after our older people ourselves if we can. It is not specifically a case of that she can’t go into a home because they are terrible or anything. It is just that we love her. This is her home. We want to keep her here” (Miss. C).

On the other hand, four carers evaluated the quality of residential care services as bad, according to their own personal experience. They pointed out a lack of staff, no programmes, cleaning issues, etc. Mrs. N experienced her uncle being put into residential care. Mrs. A lost her mother while she was in respite care. These negative experiences influence their attitudes towards the utilisation of residential care.

“My uncle was in a private care home. I don’t feel he had any care whatsoever. He was left in dirt. ... I do think this private nursing care has been crap up until today. I only had this one experience. But I found it unacceptable” (Mrs. N).

“I don’t like the personal care at care homes. She was only in respite care for four hours and they lost her. She went out on her own. I just think nobody is better at taking care of her than me. (If the residential care service was better, would you use it for your mum?) No, I do not want to leave my mum” (Mrs. A).

Accordingly, carers who are unwilling to use residential care have a stronger negative evaluation of care services. In order to remove negative experiences, the quality of care should be guaranteed. In fact, there are inspections twice a year based on Care Standards. The results can be accessed by the general public and, therefore, carers could

view the inspection results when deciding whether to use residential care. This will improve carers' attitudes towards residential care.

Six out of seven carers who do not want to use residential care also pointed out that there is no stigma attached to residential care as there was in the past. One carer mentioned that the services of residential care or abuse stories could cause stigma to be attached to it, but this is changing due to Care Standards. Moreover, using residential care no longer involves social stigma, which means carers believe that people do not criticise those who use residential care because more people are using it nowadays, and it depends on individual circumstances.

“(Stigma) Not so much now, there definitely used to be. I think on the whole people are much more open to using facilities that are available. They can’t look after older people at home or choose not to, and that is their choice. You can’t make a judgement about people as to whether they should or shouldn’t look after their family at home, because you don’t know what the relationship has been like up to that point. It is very much an individual thing. Generally, many more people are happier with the idea of support when they are struggling to look after elderly people themselves. (What things help to reduce stigma?) Commitment to care, carrying out inspections and supportive staff. A lot more money is spent on staff training now than many years ago. They are better supported” (Miss. C).

“I don’t think there is any criticism (about using residential care). Nobody can criticise it because someday they might have to put their parents in a home. You just don’t know how life will turn out. I am not aware of any criticism from anybody” (Mr. G).

Most Scottish carers in this study agree that the stigma of a care home being like a poor house no longer exists. However, one carer pointed out older people do attach a stigma to residential care. This is because the older generation may have experienced the poor house in the past.

“Older people now live in their own house. Once upon a time, they either lived with relatives or were put in a poor house, which was simply an institution. (Do you think today’s residential care gives people the same feeling?) A lot of people have that attitude and do feel it is the same as it used to be. They feel abandoned by their relatives” (Mr. J).

One carer mentioned the expense of residential care was a barrier to older people who wanted to use it. Miss. C has experienced many older people who desperately need residential care but the sell house policy discourages them from using the service.

“Older people worry about money. We’ve got to know a gentleman who really can’t take care of himself. He really would benefit from being in a nursing home but he won’t go because he’s frightened to sell his house and of the costs involved. That is the only thing that is holding him back. He loves company and loves having meals in respite care. ... He just won’t want to live there permanently because of the money factor. It does impact hugely on these people” (Miss. C).

Six out of seven carers are strongly against the expensive fees of residential care and the sell house policy. They believe that the state should provide free residential care for older people to reward them

for having devoted their lives to working hard and paying tax. They believe that state care for older people is their social right.

“I think it (sell house policy) is rubbish. They shouldn’t have to sell their house (for residential care). They work all their lives so why they should have to pay for their care at the end of their lives? I do think it is wrong” (Mrs. A).

“I’ve paid tax all my life and still pay tax. My wife and I worked and paid tax all our lives. So you expect the government to help you when you experience difficulties financially” (Mr. G).

Mrs. N was also very against the sell house policy and paying for residential care. She insisted that free residential care should be available and even suggested raising taxes to enable free care for the elderly.

“We have a national health service, which people like my mum and my uncle paid into all their lives. ... I don’t think they should have to pay. I think they should be looked after well because they paid national insurance all their lives. ... Why should we work hard all our lives to have a better standard of living and then have to give everything up towards the end of our lives to pay for our own care. Everyone should pay a little bit more from their salary towards national health. I would be quite happy to pay more” (Mrs. N).

In a nutshell, many carers do not want to use residential care because of a strong family relationship, a community services package provided at home and low quality residential care services. In this study, four adult children want to maintain care in the home. Three of

the older people with dementia live with their adult children, and two adult children carers even moved into their parents' home to look after them. These carers have a very close relationship with their parents. Moreover, they have a strong motivation to look after them. What is more, the community care package has helped them to continue to keep their relatives at home. Four out of seven carers felt that residential care services were bad, and had had a bad experience of residential care that influenced their attitude towards using it. Nonetheless, six of them thought there was no longer any stigma attached to residential care in terms of it being similar to a poor house. They mentioned that other people could not criticise carers who decided to use residential care because many people use it and someday they may need to use it themselves. Carers criticised expensive residential care fees and the sell house policy. They gave the same reasons for this as the carers who wanted to use residential care.

Summary

At present, nobody in the Scottish sample wants to use residential care. However, half of the Scottish carers said they would like to use residential care in the future. There were both similarities and differences between carers who want or do not want to use residential care.

The similarities are feelings of guilt, being against the expensive residential care fees and the sell house policy, help from community care services, and no stigma being attached to residential care or its users. The differences are evaluation of quality of residential care services, motivation and living status, for example living apart from or with relatives.

In terms of similarities, both groups of people felt guilty about using residential care because older people with dementia are loved ones. They are also very against the expensive residential care fees and the sell house policy because they think that older people should receive free residential care. This opinion originates from the belief that welfare is a social right for older people and from previous experience of the NHS. They pointed out that older people with dementia paid tax and national insurance, so why should they pay for residential care or sell their house. Moreover, they stated that they used to receive free residential care from the NHS and, therefore, they were very against current residential care fees and think the state should provide universal free residential care for all older people. This shows how the institutional welfare system affects carers' consciousness.

Both groups of people mentioned that community care at home was very helpful in delaying residential care and being able to keep their relative at home. They also mentioned that there was no longer any stigma attached to residential care as being similar to a poor house.

Stigma influences people's behaviour and involves condemnation from others (Scheff, 1990; Mackenzie, 2006:234-235). Stigma generally engages negative prejudice from society and stems from social institution or culture. The majority of carers said that there was no stigma attached to residential care or its users and thought that generally, people could not criticise others who decided to use residential care because some have no choice. Moreover, approximately 70% of respondents had the general attitude toward community care that they would choose a care home or special housing as the preferred option for an older person with dementia (Curtice and Petch, 2002)³⁶. Therefore, carers could agree that there is no stigma attached to residential care.

³⁶ Where would it be best for the person to live?

	Older person with dementia
Own home	22.9
Family	6.3
Special housing	29.0
Care home	40.1
Hospital	0.9
Other	0.3
No answer	0.5

Source: Curtice and Petch, 2002:16, Scottish Executive Social Research.

Who should care?

	Older person with dementia
Family	20.7
Friend	4.4
Nurse	14.7
Home help	58.3
(Volunteer)	0.8
Someone else	0.5
No answer	0.6

Source: Curtice and Petch, 2002:19, Scottish Executive Social Research.

There were obviously different attitudes towards the quality of residential care services. Carers who wanted to use residential care were more likely to say that residential care was good or more or less good, while carers who did not want to use residential care were more likely to say that it was bad. Carers in the group who would not use residential care seemed to have slightly stronger motivation to care for their relatives. In terms of living status, carers who lived with their relative would not utilise residential care, whilst those who lived apart would.

6.2 Carers' Attitudes towards Residential Care in Korea

Attitudes towards residential care in Korea

I found there is no significant difference in attitudes towards residential care between Seoul and Suwon. However, a higher number of carers in Suwon are willing to use residential care than in Seoul.

Table 6-2 shows that 9 out of 28 Korean carers want to use residential care at present, and 7 of these are from the lower income group. In future, 17 out of 28 carers want to utilise residential care, and 10 of these belong to the lower income group. Those in the lower income groups tended to be more willing to use residential care

compared with those in the higher income groups in Korea. Lee (2004) argued that families in lower income groups would prefer to use formal care services. Choi (2004) also pointed out that people who felt their personal income status was low were more likely to demand a residential care service. The reason why lower income groups are more likely to prefer to use residential care or formal services is that they are entitled to free long-term care services.³⁷ It means that they do not worry about the affordability of services. The result from my sample shows the similar results to these previous studies.

In Seoul, 4 carers want to use residential care right now, and 3 of these are in the lower income group. The number of carers who would be willing to use residential care in the future was higher, 8 out of 14, with 7 of these being adult children, grandchildren or nieces. Moreover, 5 carers in the lower income group would use residential care whilst only 3 carers in the high income group would use it.

In Suwon, 5 carers want to use residential care at the moment and all except one are in the lower income group. In the future, 9 out of 14 carers would want to use residential care, and 7 of these were adult children and nephews. Five carers in the lower income group would use residential care while only 4 carers in the higher income group would want to use it.

³⁷ On the other hand, there are many factors related to social welfare systems as an institution: community care at home, accessibility of community care services information, delivery of services, utilisation of services and evaluation services, and residential care (refer to Chapter 5 & 6).

Table 6- 2 Attitudes towards utilisation of residential care in Korea

City	Income	Case	Present	Future
Seoul	H I	Mrs. A1	No	Yes
		Mr. B1	No	No
		Mr. C1	No	No
		Mr. D1	No	No
		Mr. E1	No	Yes
		Mrs. F1	Yes	Yes
		Mrs. G1	No	No
	L I	Mrs. H1	No	Yes
		Miss. I1	No	No
		Mr. J1	No	Yes
		Mrs. K1	Yes	Yes
		Mrs. L1	Yes	Yes
		Mr. M1	Yes	Yes
		Miss. N1	No	No
Suwon	H I	Mrs. A2	No	Yes
		Mrs. B2	No	Yes
		Mrs. C2	Yes	Yes
		Mr. D2	No	No
		Mrs. E2	No	No
		Mr. F2	No	Yes
		Mrs. G2	No	No
	L I	Mr. H2	Yes	Yes
		Mrs. I2	Yes	Yes
		Mrs. J2	Yes	Yes
		Mrs. K2	No	Yes
		Mrs. L2	No	No
		Mrs. M2	No	No
		Mrs. N2	Yes	Yes

Carers, whether they want to use it or not, were recommended to use residential care by others, for example family members or neighbours, etc. in Seoul and Suwon.

“My friends and even my mum’s friends recommend that she should be sent to a facility as caring for her is taking over my life” (Miss. N1).

“It’s so hard to take care of my aunt. My eldest brother said it would be better to send her to a facility” (Mr.H2).

Some carers accept the suggestion but many do not at present. The discussions in the next section explain why some carers desperately

want to use residential care, some want to use it in the future and others disagree with using it at all.

Willingness to use residential care

Seoul

Four carers agree with the suggestion at present, and are desperate to use permanent residential care due to difficulties with coping with the care and their work. Even Mrs. L1 looked for help, but a lack of residential care delayed institutionalising her mother-in-law. Mr. M1 is also eager to use residential care, but a lack of placements is holding this up and forcing his grandmother to remain living in the community.

“I was considering using residential care because I could not cope with work and caring. It is very hard to deal with a job and care for someone... I tried to put my mother-in-law into a facility but it may take about one year because there is no room for her” (Mrs. L1).

“I looked for a long-term residential care home for my grandma. However, the institute refused to receive her because the facility was not good for my grandma, so she cannot go there” (Mr. M1).

This shows that a lack of residential care placements delays people using the service in Seoul. Carers who want to use residential care are in the lower income group. The Korean means-test for NBLS includes the adult children’s income. Therefore, carers in the lower income groups are also poor. Thus, they could not give up their job, and this may result in risks for carers and older people. Carers in this situation

are very distressed because they have to deal with work and their caring role. Moreover, carers could not provide proper care if they work as well.

Eight carers would be willing to use residential care in the future, but they mentioned that they were concerned about doing so when their relatives became worse, especially if they became incontinent.

“I am considering residential care. If her condition gets worse, for example she cannot recognise me, I will make sure she is taken care of in a good residential care home” (Mr. E1).

“From time to time I think about sending my wife into residential care because it’s a very difficult job looking after her” (Mr. J1).

When the older couple live together, it is hard to separate them. One carer who looked after her parents said that when one of them died, she would consider using residential care.

“If one of my parents dies then I will think about using residential care” (Mrs. A1).

Carers mentioned that social services at home and other family members’ help assisted in enabling their relative to stay at home.

“If it is possible for a home helper to take care of my aunt at home, I would like to live with her” (Mrs. K1).

Mrs. H1 even searched for a care home for her mother, but her mother received day care services that enabled her to stay at home.

“It’s so difficult to look after my mum with my job. I used to try to look for an authorised care home. Now my mum lives with her sister and uses the day care centre. She doesn’t use any care home” (Mrs. H1).

This shows that community care services do affect the delay of the utilisation of residential care.

Carers and their families feel guilty about using residential care, even though they want to use it. The feeling of guilt is a pressure for carers and delays the use of residential care.

“I told my sister we should send our mum to a care home. My sister cried at the time and said, ‘Why must we do that? How many children are there!’” (Mrs. F1).

However, carers are willing to use residential care even though they feel guilty about doing so. Mr. M1 pointed out that he felt sorry about having to use residential care but his situation did not enable him to look after his grandmother. Therefore, he wanted to use it. Mrs. K1 felt guilty using residential care but she had the dilemma of trying to balance her life with caring for her aunt. However, a heavy burden of care affected her willingness to use residential care.

“I don’t think there is a bright side to putting my grandma in residential care. It’s natural for me to do it though as my situation is not good. So I will try to find a proper facility” (Mr. M1).

“I am distressed about putting my aunt into a residential care home, but I’m sixty years old so it’s so difficult” (Mrs. K1).

An evaluation of care services is important to carers’ attitudes. All carers in Seoul who are willing to use residential care have a fairly positive attitude, and 5 said that residential care would be good and 3 thought it would be fairly good. Carers who wanted to use residential care also tended to have a positive evaluation of the care services, and thought that it provided professional care.

“Hospitals and care homes have improved, haven’t they? It is better for my parents to go into residential care than stay at home, because there are professional carers there all the time with them and other old folk as well” (Mrs. A1).

“I can work without worrying because there are experts and nurses who will take care of my mother-in-law. It makes me feel very comfortable” (Mrs. L1).

Most carers said that residential care was a good idea for their relative with dementia because they could make friends and do more activities. In fact, older people with dementia without a full time carer and community care services are more likely to suffer harm and be at risk. The situation obviously shows that there is a certain neglect for older people with dementia. Therefore, carers believe that residential care is better for their relatives.

“Residential care is better because my mother-in-law can make friends in the facility. In her house, frankly, she is left behind” (Mrs. L1).

“My parents haven’t done anything at home since they moved into my house. It is not good for them. If they go into residential care, they can meet friends and engage in activities. It will be better for them” (Mrs. A1).

Previous studies argued that the stigma based on Confucianism was significant in terms of Korean carers’ attitude. However, carers in Seoul said that these days, there is no stigma attached to people who use residential care in Korea.

“Although I am a more conservative person than other people my age and my friends, I would decide to use residential care if my wife and I could not cope with caring for my mother. I think nursing homes today are very good. I have seen many nice care homes on the TV” (Mr. E1).

“These days, many people see it from a positive perspective. They tend to think it’s better than leaving a person alone. This is totally different from the past” (Mrs. F1).

“Most of my family members agree with using residential care. Nowadays, the attitudes towards residential care have changed” (Mrs. A1).

Affordability is an issue regarding the use of residential care. In Seoul, only one adult child carer said he had no financial burden due to using residential care because his mother received a pension from his father.

“My mother is a pensioner so there is no economic burden” (Mr. E1).

However, most carers said the residential care fees would be very expensive. One carer pointed out that expensive residential care fees influence the delay in older people with dementia entering care homes.

“I have obtained information about long-term residential care but it’s too expensive. My brothers are older so cannot earn money. I’m also over 70” (Mrs. F1).

People in the lower income group also agreed that because they only receive a general salary they could not afford the residential care fees. Moreover, they felt very fortunate to be entitled to use free residential care.

“Luckily, my mum can use the facility without any payment, but other people feel a big burden because it costs around 7 hundred thousand won. It’s a big burden for the public. My friend put her mother in a residential care home but the fees were left unpaid for several months” (Mrs. H1).

“My mum has recently started receiving government subsidies. I am very thankful. Usually, the fees cost one million won per month. I cannot afford to pay this in my situation” (Mrs. K1).

Mr. J1 and his wife are entitled to NBLIS and, as a result, his wife could receive free residential care. However, nobody told him about the free residential care and consequently, he did not know whether he could receive it or not. This again shows the lack of information available about social services in Korea.

“There are fees for the use of residential care, aren’t there? If so, I cannot go there... If it’s free, I would like to use it very much” (Mr. J1).

Five carers believe there should be state participation towards long-term care as a charity rather than a social right, and three of these carers felt that the government should contribute to the residential care fees even if they cannot consider free residential care for all older people. However, they want more support from the government than there is now.

“I don’t think the use of residential care should be free but the government should help more people be able to use the facility” (Mr. J1).

“If there is a patient in the family, the family faces economic difficulty. In the case of poor people, like me, the poverty transfers to the next generation. If a family has all the responsibility for caring for an elderly person with a long-term illness, it will collapse. Therefore, the state should take responsibility for caring for older people” (Mrs. H1).

Most carers, except those who are in the lower income group, have never experienced free services from the state. Moreover, carers in the lower income group have also had to pay some hospital charges depending on what the service includes. Therefore, they are not expecting free residential care from the state. This shows how the welfare system in Korea influences carers’ attitudes towards residential care.

Suwon

Five carers want to use residential care at present, and two of these have even applied for it but could not get places because of the waiting list. Mrs. A2 is also waiting for residential care. She even used unpermitted residential care because she struggled with caring and working at the same time.

“I wish there were more facilities managed by the government. It’s so difficult to get an opportunity to use residential care because a user who enters the facility does not leave it until they die. Most of patients have to wait to enter the facility until he doesn’t go to toilet by himself (which means that patients wait until they have urinary incontinence or severe disability)” (Mrs. A2).

A lack of community care services influences people’s attitudes towards residential care. Mr H2’s aunt needed to change her incontinence pad regularly. The home care service was only provided for four hours a day, which did not cover the period when he was at work. As a result, she could make a mess during the absence of care. It was very hard for him to look after his aunt alongside his career. He desperately wanted to use residential care but the long-term care facilities had long waiting lists, so he cannot use it at the moment.

“Care home services can be used for just four hours a day. So until I come back home, my daughter cares for her or she is alone. My aunt has urinary incontinence, so I have tried to find a relevant facility for her. But it takes a long time, about a year, for a long-term care facility to become available” (Mr.H2).

Mrs. J2 also wanted to use residential care but her mother's condition does not yet entitle her to it. In fact, the relationship between Mrs. J2 and her mother was not good, which is one reason why she wanted to use residential care, but Mrs J2's mother received a 3rd degree long-term care, which entitled her to community care services except for residential care. She has to wait until she receives a 2nd or 1st degree.

"I do not feel much affection for my mum. Since I was a child, I have lived away from her. I am now obliged to look after her because she gave birth to me and my sister cannot take care of her. But no facility will accept her because her condition is not serious enough" (Mrs. J2).

However, a poor relationship could cause a higher level of distress for carers. The burden of caring results in older people with dementia being mistreated while they are waiting for residential care. Formal care involvement is significant to prevent abuse or neglect of older people with dementia at home (Phillips et al., 2000). Therefore, community care should support someone with a case like Mrs J2 in order to reduce her burden of care.

One carer mentioned that applying for residential care would be very difficult because of a lot paperwork. Moreover, her mother, who has been bedridden for a long time, needed a health check-up in order to apply for residential care and, therefore, her mother needed a wheelchair to take her to hospital. However, she did not have a

wheelchair, which made it difficult to prepare the necessary paperwork.

“I would like to send my mum to a facility because I cannot take care of her very well, whereas the facility will provide her with a good service... But it’s not easy to apply for residential care. This is because I need to get a medical certificate for the application. But it’s so difficult to take my mum to a hospital for an examination because we have no wheelchair” (Mrs. N2).

Carers are very busy caring for relatives and dealing with their own life and job. Applying for residential care should be made more simple. Moreover, a visiting service by a nurse or doctor should be provided for older people who are bedridden. Thus, they could get health check-up documents to enable them to apply for LTCI.

Nine out of fourteen carers are willing to use residential care in the future. They mentioned that they would consider using residential care when their relatives lost consciousness or became incontinent.

“I take care of my mother, including her faecal and urinary incontinence. I will try to do what I can, but if I become too worn out, I will put her in residential care” (Mr. F2).

“I would like to take care of my husband for as long as I can. But, I will get older and older and, someday, will have to use residential care” (Mrs. B2).

Carers felt guilty about using residential care, but the reality of the situation forced them to choose that option.

“A sense of guilt prohibits me from putting my husband in residential care. We have lived together for a long time with conjugal affection. But I want to use a facility because I find it so hard to look after him” (Mrs. A2).

“My aunt has looked after my children, so I cannot put her in a facility because I love her and would feel a sense of guilt. Yet, after I go to work and my children go to school, there is no one to care for her. A home helper provides only short-time services” (Mr.H2).

One carer mentioned home help as LTCI. Mr. F2 wanted to use residential care at the beginning, but his mother was rejected due to her behavioural problems. Since then, he has received community care at home. Now, he takes care of his mother at home, although he is not very satisfied with the home helper.

“I would like her to be cared for in residential care, but the facilities rejected my mum because of her serious symptoms of dementia. I now receive home help services, but it’s not enough” (Mr. F2).

Seven carers said that the quality of residential care services were good, whilst one said they were fairly good.

“Families have a limit when looking after their parents who need long-term care. It can be better to use residential care for parents, as the staffs in nursing homes are educated and professional so they can make older people more comfortable. However, it is very expensive and for us that is a problem” (Mrs. C2).

“Care homes are clean and are medically equipped. They are good for older people because they can play and enjoy daily activity programmes” (Mr.H2).

Carers stated that residential care is a good alternative option for their relatives because they will be provided with professional care.

“The residential care system may be better for my husband. The system is more professional than our family. The staffs in the facility are professionals who can make good conversation and have systemic education in caring. Families are not professional people. A protracted illness gradually erodes filial devotion, and can make a good relationship bad” (Mrs. A2).

“Frankly, filial piety is to send her into residential care, because the nursing is better there. We would definitely do it in the case of a mental disorder” (Mr.H2).

Carers’ emphasis on social stigma attached to residential care has disappeared in Korea. Carers who want to use residential care strongly emphasise that no stigma is attached to residential care and justify their excuse to use it due to the distress of caring for older people with dementia.

“In the past, television showed the abuse of older people, old facilities and low quality of service in residential care. So I swore that I would never use residential care for my parents. But these days, there are many private nursing homes, which have been developed. The environments of nursing homes are now very pleasant” (Mrs. C2).

However, Mr. F2 stated that he felt a stigma is attached to residential care and its users. He even distrusted residential care services and said he would therefore keep his mother at home for as long as he could.

Although he felt distrust towards residential care, he would eventually use it because of the burden of caring for someone with dementia.

“My neighbours recommend that my mother is sent to a residential care home, and I might agree with their opinion if she was not my mother. ... This is a kind of an ancient practice of abandoning an old person to die. If I put her in a facility, it will be so difficult to see her, maybe only once a week. Therefore, I will look after her for as long as possible. That’s why it’s a filial duty. ... I don’t trust social facilities... I have visited the Central Nursing Home and there is one room for four people. And what a surprise, there is only one nurse responsible for not one room but two or possibly three rooms. Is it possible for a person to take care of too many patients? There are, I think, no proper professionals there. It’s place where people go to die” (Mr. F2).

One carer pointed out that LTCI worsens the burden of residential care fees. It can be argued that older people with dementia should receive a 1st or 2nd degree of long-term care (see table 5-2). Some older people have late moderate dementia or severe dementia and could otherwise be physically healthy. Therefore, their degree of long-term care is underestimated. It is difficult to meet the appropriate entitlement of residential care for older people with dementia. In fact, LTCI receivers are 3.9 per cent of total older people population although people who are in need are more than 8 per cent of total older people population.

“In terms of facilities, a patient with a 1st or 2nd degree pays seven hundred thousand won (350 pounds per a month) but people except those with a higher degree should pay twice as much, exactly one million and sixty

hundred thousand won (800 pounds per a month). It's difficult with dementia to estimate the degree because the appearance of the body is not that bad. But, it is a difficult job to care for elderly people with dementia" (Mrs. C2).

Mrs. B2 felt that residential care fees were very expensive. She even worries about this even though she lives in a very big apartment and owns several shops. She receives her income from letting these shops.

"I cared for my parents-in-law and brought my children up. Now I am caring for my husband. I have been cooking and doing domiciliary work at home all my life. I don't want to do it any more. Actually, I was planning to put my husband in residential care but something did not go well and therefore we are unable to afford it" (Mrs. B2).

Other carers also felt that residential care fees were expensive and, therefore, some carers have heard that people refuse to use it even though they are unable to look after their older relatives at home.

"There are many facilities in Suwon, whose deposit is between twenty and thirty million won. In addition, the monthly rent is between one million and twenty hundred thousand to one million and fifty hundred thousand. The facilities are too expensive" (Mr.H2).

"If my husband were sent to a care facility, it would be no good. I would be very comfortable, but the fees are very expensive. They reach around one million won. With the help of my daughter, I am able to pay the fees, but I find this very difficult. In this situation, the government should give me some benefits. Truly, I don't like having to rely on my daughter" (Mrs. A2).

Mrs. J2 felt fortunate not to have to worry about residential fees because her mother was entitled to free residential care. She criticised the payment required for LTCI.

“Luckily, we are entitled to a discount ticket for residential care. So I pay just 20 per cent of the expenses. But it’s still seven hundred thousand, so it’s still a big burden. I wish the expenses were lower than the minimum level” (Mrs. J2).

Two carers thought that they had a right to receive free residential care, whilst seven said that if they did receive free services, they would feel like a charity. However, they would still like more support from the state. Most carers, though, did not argue for a universal free residential care service for older people.

“Of course, the benefits from the government are very helpful to us, but I don’t expect any free benefits from the government for older people, even though it is, to some extent, responsible for people in society” (Mrs. C2).

Mr. H2 insisted that the state should provide more free residential care for poor people and extend the entitlement of free care.

“The poor older people are rejected the entitlements of social assistant because they have adult children. The government should provide homes for people who have nowhere else to turn” (Mr. H2).

Briefly, there are no significant attitude differences between Seoul and Suwon although long-term care pilot scheme has been introduced in

Suwon . LTCI pilot scheme reduces the price of residential care fee but it is still expensive for carers and older people with dementia.

In detail, nine Korean carers want to use residential care at present and seventeen would use it in the future. Carers choose to use residential care because of inadequate community care at home, difficulty in coping with caring and working, the distress of caring, the better quality care available from residential care and the lack of stigma now attached to residential care and its users.

Carers in the lower income group are more willing to use residential care than those in the higher income group. Lee (2004) and Choi (2004) argued that families in lower income groups would prefer to use formal care services or residential care service due to free entitlement of long-term care services. The result from my sample is similar to these previous studies. However, interviewees with low income in my sample present that demand for residential care not only for free entitlement but also for the sake of carers' living. It means that carers in lower income group face dilemma for their work and caring in Korea. The carers in lower income group also are very poor thus they have to work for their bread.

In terms of the quality of residential services, most carers thought it provided good services. Moreover, many carers said there was no longer any stigma attached to residential care and its users. In terms of residential care fees, most carers said that they thought these were very expensive. An exception was one carer in Seoul who said

he did not feel burdened by the residential care fees because his mother received a pension from his father. Besides, carers were very distressed because of a lack of community care at home, which encouraged them to use residential care.

Unwillingness towards using residential care

Seoul

Seven carers said they refuse to utilise residential care in Seoul. Carers have various reasons for rejecting residential care, including the quality of the services provided, losing benefits, if they have enough support at home, feelings of guilt, etc. Miss. N1 mentioned that she would not accept residential care because staff there would not be able to feed her mother, who has severe dementia and needs a lot of time to be spent on encouraging her to eat.

“I have a positive opinion about facilities, but for a person with serious symptoms it may not be a good idea. My mum should be cared for from morning till night, so she would not be safe in residential care. When she was in hospital, my mum had a helper who did not give her any more food when my mum refused it. Nevertheless, she should have kept trying until she ate something. Therefore, I hesitate in sending her into residential care” (Miss. N1).

Miss. I1 copes with her mother who has dementia, but she would not accept this because she was afraid of losing the financial help she was receiving from the government.

“If my mum uses residential care, the government subsidies cannot be obtained. In this case, our life would get worse. So I would like to care for her despite the difficulties” (Miss. II).

Home help services have enabled Mr. D1 to continue caring for his mother and have influenced his attitude towards residential care. When his mother was discharged from hospital, he searched for residential care near to his house. However, there was no place for his mother due to a lack of beds. Finally, he received home help services, after which he would not accept residential care. Mrs. G1 also mentioned that respite care has helped to keep her father at home.

“When my mother was discharged from hospital, I didn’t know whether home help services were available. Now I am receiving the services, and if I had known about them before, I would have discharged her from hospital sooner” (Mr. D1).

“If it becomes very difficult, I will take a rest by using respite care. I would like to care for him until he dies” (Mrs.G1).

Mr. B1 refused to use residential care as he had two private carers so he could cope with caring for his wife at home. However, he has researched residential care in the past but found that it was not good enough for his wife. Moreover, his children were against the idea of residential care, and therefore he decided to care for her at home.

"I visited three or four hospitals and facilities. They were not clean. An expensive facility is not for caring but for management. If there were a facility in my town that had a kind of harmonious family atmosphere, I would have sent my wife there. If I decide to send her, my children will make a stand against it" (Mr. B1).

Feelings of guilt from using residential care influences carers to not use it. Mrs. G1's father was in residential care but she felt very guilty and therefore decided to bring her father back home.

"My father used to be in a facility. When I put him there, I had a heavy heart on the way back to my house. After that, I saw him in the facility once but that was enough. Of course, the staff in the facility took great care of him, but I suffered from a guilty conscience. He brought me up to carry on his back (Korean expression that means her father brought her with all his heart and soul). I thought that if he died I must repent. How long would he live for? I would like to care for him with no regrets. This is also a great education to my children" (Mrs. G1).

The majority of carers had positive attitudes towards the quality of residential care services, for example, one thought residential care was good, three carers felt it would be more or less good and only one thought it would be bad or that it would be not as good as family care. Carers emphasised that their relatives would lose out if they used residential care. Moreover, carers pointed out that the distance between their home and the residential care affected their feelings about putting their relatives in care.

“The services in residential care are very good but my family is better than the facility at providing care” (Mrs. G1).

“There will not be many visits when my mum goes into a facility because it’s so far from here. I wish the facility were near my house. I feel like I am leaving her behind. I can’t do it, as I have a conscience” (Mr. D1).

One carer still feels there is a stigma attached to residential care. Whenever they talk about this, they mention the fact that the residential care environment is such a long way away. He felt like he was abandoning his parents because the residential care was far away from his home.

“As long as I live, I will take care of my parents, because the facility is so far from here it would be like abandoning them. It’s a kind of an ancient practice of abandoning an old person to die at the gravesite. Until now, the welfare system of our country is in low level” (Mr. D1).

On the other hand, most carers in Seoul mentioned that they felt there is no stigma attached to residential care services, but that the standard of the services should be properly inspected.

“I think there is a good quality of services and no stigma attached to residential care. I do think there are many problems though in aspects of management and leaving elderly people alone” (Mr. B1).

One carer discussed affordability of the residential care fees. Mr. C1 was unemployed and his wife had a full-time job but he felt that he

could not afford the fees. Mr. Jung also said that the expensive residential care fees were a heavy burden for his family.

“Everyone has told me that residential care fees are very expensive, around three million? It’s incomprehensible to me, and a big burden” (Mr. C1).

“I heard it’s two million per month. It’s ok for a rich man, but I can’t afford it” (Mr. D1).

Four carers considered state participation in residential care for older people was a charity rather than a social right, and two of them pointed out that the state should be responsible for residential care fees because it was a social right. However, most carers expect a contribution to residential care fees rather than free residential care.

“It’s not recognised as a right to use residential care and receive social services. Nevertheless, I would like to be able to use those kinds of services and benefits” (Mrs. G1)

“Caring for elderly people with dementia is so difficult for the individual. So I think the government should be responsible for this problem. We have paid tax all our lives” (Mr. C1).

Suwon

Five carers in Suwon were unwilling to use residential care, and their reasons include strong motivation, criticism from other family members, community care support, affordability and quality of residential care.

Some feel a strong motivation to continue to care for their parents. Mrs.L2 refuses to use residential care because she feels compassion for her mother. Mr. D2 also mentioned that he would not accept residential care for his mother and will continue to care for her with home help services. He felt it was his obligation to looking after his mother at home.

“Past thoughts disappear now. It’s not a filial duty to care for our parents in a residential care home. Now people don’t think like this. But, I would like to take care of my mum not out of duty but because of my affection for her. She has had a life full of hardship” (Mrs. L2).

“I have no problem with a social facility but it’s better to take care of her in my own house. Until she dies, I will look after her. That’s what children should do” (Mr. D2).

Mr. D2 is a very traditional man, but he states that he wants to use community services to be able to keep his mother at home. This shows that carers in Korea want to use formal services even if they feel strong filial piety.

Mrs. G2 said that she wanted to use residential care but worries about receiving criticism or blame from other family members. She sacrifices herself to keep harmony with her family. It reflects the Confucian culture that still exists in the Korean family.

“I used to consider the use of facilities for my mother-in-law. But it’s impossible because my sisters-in-law wouldn’t like it. I have cared for her until now, so I have

decided to do it forever. It's about making peace in our family. I dislike that kind of criticism from them. Truly, I can't send her to a facility due to this blame and positive opposition I receive from the family" (Mrs. G2).

Carers fear that their relatives will feel abandoned. Mrs. M2 was distressed about the idea of residential care. She explained that it would break her mother's and her heart. She received home help services and her religion helped her to keep her mother at home.

"Putting my mum in a facility would give her a shock. Likewise, I cannot send my mum to a facility because it will hurt her feelings. I think God will bless me when I take care of my mum. These days, home helpers give me time to relax. It's good" (Mrs. M2).

Some carers have already mentioned that the home help services influenced their attitudes towards residential care. One carer stated that carer allowance would be good idea for carers who look after their relatives at home. In fact, LTCI does not provide carer allowance. Carers, especially those who do not use residential care even though they are entitled to it, feel that the system is unfair to them because they do not receive any benefits.

"Although my mum's condition has become serious, I would like to care for her in my house because I dislike the idea of putting her in a facility. In this case, the government does not provide any benefit because my mum is in my house and not a residential care home. It's not right. A patient who has to be sent to a facility but stayed at home and cared by family should be, I think, entitle to subsidies just like a patient in residential care. It's necessary" (Mr. D2).

Some carers have issues about the standard of residential care services in relation to their affordability. Mrs. E2 agreed to use residential care, but she would not accept it now because of the poor quality of residential service and home help. Mrs. E2's husband thought that residential care where they could afford it would be a last resort for his mother. Moreover, home help services have allowed Mrs. E2 to continue caring for her mother-in-law.

“After a LTCI pilot scheme in this area, my husband's brothers hesitated about whether my mother-in-law should be sent to a residential care home. Therefore, I tried to find a facility for her. My husband and I are not satisfied with a facility whose expenses total one million per month. At least facilities from two or three million per a month are good quality residential care for her (which they could not afford). In addition, the poor quality of facilities means that four or five people are in one room. My husband feels very sad when he thinks about this facility. I have decided to take care of her at home” (Mrs. E2).

Three carers in Suwon said that residential care was good or fairly good, whilst two said it was bad. Some carers said that the quality of residential services had been improved. Mrs. E2 said that the quality depended on money, whilst Mr. D2 is suspicious of private residential care.

“The facilities are getting better but are expensive” (Mrs. E2).

“There is little difference between facilities. In general, it’s more convenient to care for the elderly with dementia at a facility. However, I did hear about one private care facility that tied its clients up and hit them. That kind of thing never happens in public facilities” (Mr. D2).

Carers pointed out there was less expensive residential care available, however, they felt residential care is expensive when care standards are met. Carers recognised that the more expensive the residential care, the better the service.

“For residential care, much money, maybe between one and two million won, is necessary. It’s ok for rich people but it’s big burden for poor people” (Mr. D2).

“I don’t want to look at it negatively, but it’s too expensive to use residential care homes that are of a fairly good quality. The costs of the facility are a big burden to me” (Mrs. E2).

Carers evaluated the residential care services. Mrs. L2 stated that there was no stigma attached to residential users because filial piety was less strong than it was in the past. All carers who were unwilling to use residential care in Suwon asserted that there was no stigma attached to residential care.

“People who are around me suggest using long-term hospital care for dementia. Although I do not use it, I agree with using residential care. A long time ago, people thought that using residential care was wrong as a result of filial piety, but this stigma has disappeared among most people. Some people said that those who send their parents to a nursing home are better than

people who leave or neglect their parents alone at home” (Mrs. L2).

Only one carer felt the responsibility for residential care should be provided by the state as a social right, whilst four saw it as charity. On the other hand, none of them insisted on free residential care or services for all older people. They just want more participation from the state.

“At this point, I thank the government for the benefits they offer. I don’t think it’s my right, but I think the government should be responsible for the protection of elderly people” (Mrs. E2).

“The government, I think, should secure welfare and facilities for the elderly. The old people have lived with a tax burden and so, naturally, the government is, to an extent, responsible for them” (Mr. D2).

Eleven carers would not want to utilise residential care in the future, and those in the higher income group are less likely to use residential care. Korean carers pointed out that the quality of services has been improved and they have a positive evaluation of the services provided. On the other hand, carers felt that expensive residential care provided better care, but they could not afford to use them. Therefore, the services in residential care that they could afford did not meet their required standard of care. Moreover, some carers said that less stigma is now attached to residential care because of weak filial piety. However, one carer pointed out that the stigma was a result of the

location of residential care, as it is usually placed outside of the community or in the city.

In terms of residential care fees, carers also felt that they were expensive. Long-term care pilot scheme is benefit to middle income people rather than poor people who are already entitled to free social service and residential care. Therefore, the poor people get any difference between long-term care scheme and present scheme. On the other hand, middle income people still need to pay a service charge, for example, residence in care home will require 20 per cent of total payment under pilot scheme.

In the case of Suwon, carers mentioned that they were considering residential care due to a reduction in charges as a result of the LTCI pilot scheme. Nevertheless, they felt that what they could afford did not match their requirements for residential care services. Furthermore, they mentioned that community care services at home have helped them to keep their relatives with dementia at home.

Summary

I looked for evidence that long term care insurance would make a difference to attitudes to residential care but I could not find any significant difference between Seoul and Suwon. In fact, lack of care services encourage to use residential care but expensive residential care fee creates a burden to carers in Suwon even though long term

care insurance pilot scheme was introduced. LTCI pilot scheme has co-payment and no package of service thus it does not make large difference in attitudes between Seoul and Suwon.

Eight out of fourteen carers in Seoul said that they would use residential care, whilst nine out of fourteen carers in Suwon said that they would utilise it in the future. Four out of fourteen carers in Seoul desperately want to use residential care while five out of fourteen carers in Suwon want to use residential care right now. The lower income group particularly wanted to use residential care, and most carers in this group were also facing economic difficulty. Therefore, they need to continue to work to be able to live, this means they struggle to cope with working and caring at the same time. Consequently, they desperately want to use residential care, but the waiting list of free residential care was too long and the acquisition of the conditions of entitlement is not easy.

There were similarities and differences between carers who would or would not use residential care. The similarities included attitudes towards the charges of residential care, social welfare consciousness and the stigma attached to residential care. The differences were strong motivation, users' income, community care at home and quality of residential care.

Regarding the similarities, carers in both groups said that residential care fees were expensive. Many older people in this study did not have a regular income, and for that reason, residential care fees

were one of reasons for their delay in being able to use residential care, even though they wanted to use it. In Suwon, carers felt that LTCI helped to reduce the residential care fees, but co-charge payments and difficulties with entitlement - 1st - 2nd degree - delays them being able to use residential care. Carers in Suwon thought that residential care fees were still expensive.

In the case of social welfare consciousness, most carers did feel that state participation in residential care was a charity rather than a social right. On the other hand, carers pointed out that the state should contribute more to residential care fees and extend the boundary of free residential care. They did not mention universal free residential care, unlike the carers in Scotland. Korean carers had no experience of free social services except those in the lower income group. This shows how the residual welfare system has an impact on carers' attitudes towards residential care.

This study shows that Korean carers believe there to be no stigma attached to residential care either in the willing group or the unwilling group. Without doubt, in the past, there was strong social criticism of the children who did not care for their older parents. The moral and ethical basis of the criticism stems from Confucianism. In this context, residential care for their parents was against the feelings of human beings in the past. The image of residential care can be found in the statements below. Firstly, it is accepted in Korean society that using residential care is want of filial piety. Lee and

friends.(1994) insist that Korean people have strong stigma attached to residential care because they still have a strong tradition of family responsibility for caring their parents. Secondly, it is recognized that the facilities are only a place for the older people without children. Moreover, the quality of present residential care is poor and simply lodge older people, thus, the older inmates feel shame and have been stigmatised by the local residents (Kim, 1990). Thirdly, it is acknowledged that the institution is a place for the poor people. There was no private residential care before 1993 in Korea. The law of older people welfare including permission of private residential care was passed on 30th of November 1993 (Lee et al. 1994; 305). Therefore, there had been only available public residential care homes which persons were entitled through means-tested till 1993. Thus, people do not want the use of residential care for their parents or spouses due to stigma attached with residential care in the past. Moreover, a recent study argues that Korean people still attach a stigma to residential care. According to a general survey of attitudes towards residential care in 2004, only 29.7 per cent of general older people aged over 65 would want to use residential care while 38.8 per cent would want to use long-term hospital care, although recognition of residential care and long-term hospital care was 84.8 per cent and 51.9 per cent respectively (Korea Institute for Health and Social Affairs (hereafter KIHASA), 2005:53). Moreover, the same study showed that if parent had long-term illness, only 4.5 percent of households in general would

want to use residential care (ibid.)³⁸. However, Korean carers in my sample tended to use the disappearance of this stigma for their justification. Besides, it could mean that carers think there is less stigma attached because of the improvement in residential care services.

On the other hand, there were differences between the groups that did or did not want to use residential care. Carers in the group who do not want to use residential care have a slightly stronger motivation and closer relationship with their relatives compared to carers in the group that do want to use residential care.

There are also income differences. The lower income group is more willing to use residential care than the higher income group. Most carers in the lower income group were also facing economic difficulty, and therefore needed to continue to work to be able to live. As a result, they struggled to cope with working and caring at the same time. Consequently, they desperately wanted to use residential care but the waiting lists were too long and the acquisition of the conditions of entitlement was not easy. Moreover, the lower income group are provided with free residential care, and therefore, services are more accessible to them and there is no requirement to pay. This shows that accessibility and affordability influence people's attitudes towards the utilisation of residential care.

³⁸ The survey was conducted by Korea Institution for Health and Social Affairs for 'Living profile and welfare service needs of older persons in Korea'. The survey stated from June to September in 2004. It was interviewed 9,308 household and 3,278 older people who were 65 years of age or over.

Both groups of people who did not want to use residential care stated that community care services were one important factor that can delay being able to use residential care. However, carers in the willing group stated that a lack of community care influenced the use of residential care, whilst carers in the unwilling group pointed out that community care helps them to continue to care for their relatives at home. Moreover, slightly more carers with a higher income in Suwon are willing to use residential care than those in Seoul. Suwon city has introduced a LTCI pilot system and, therefore, the residential care fees have reduced. This has influenced carers' attitudes towards the utilisation of residential care.

Carers in the group that wanted to use residential care stated that it was good or fairly good. In contrast, some carers who were unwilling to use residential care mentioned their dissatisfaction with it. Moreover, carers in the unwilling group said that their requirement for quality services in residential care is not matched with their affordability. They cannot afford the residential care they want. They believe that the more expensive the service, the better the service.

6.3 Summary

This chapter has explored the attitudes towards residential care in Scotland and Korea. There are similarities and differences in carers' attitudes towards between the two countries.

With regard to the similarities, the first is the evaluation of residential care services between Scotland and Korea. Carers who tend to hesitate about the use of residential care have negative attitudes towards the use of it, whilst carers who would use residential care tend to have positive attitudes towards the quality of services in Scotland and Korea.

In addition, carers in both Scotland and Korea feel the burden of guilt for the use of residential care. This is a very interesting finding, because it was expected that the two countries would be different. Scotland provides sufficient services in residential care compared to Korea, and because Scotland and Korea are based on individualism and Confucianism respectively, they must have different views about the services. Therefore, it is clear that this difference will create a different attitude towards residential care. However, it was found that people in both countries have the same feelings of affection and sense of guilt about their parents and using residential care.

Moreover, there is similarity in terms of the social stigma attached to residential care and its users, although there is less social

stigma in Scotland than in Korea. Unlike previous studies (Jeung et al., 2005: Kim, 1990; Lee et al. 1994), this study shows that Korean carers believe there to be no stigma attached to residential care. Moreover, the willing and unwilling groups have quite similar attitudes towards this issue. Carers in this study tended to say that there was no stigma attached to residential care because of their justification. Moreover, this could be because residential care services have improved

Regarding the differences, there is a different preference for residential care in the two countries. No Scottish carers want to use residential care right now, while nine Korean carers would like to use it now. Seven out of fourteen people in Scotland would like to use residential care in the future compared to seventeen out of twenty-eight people in Korea. This shows that more Korean carers want to use residential care than Scottish carers. Why is this? One reason is community care, as in Korea there is the lack of community care services at home compared to Scotland. Therefore, Korean carers feel more strongly about wanting to use residential care.

In addition, there was a difference in social welfare consciousness. Scottish carers recognised government support for residential care as a social right whilst Korean carers admitted they saw it as a charity. Therefore, Scottish carers have higher expectations about government participation in residential care fees, and argue that the state should provide people with free residential care. Whereas

Korean carers insist that the state should reduce the fees for residential care, which shows that Korean people recognise that the financial responsibility should be shared between individuals and the state. Therefore, Scottish carers feel more angry about residential care fees than carers do in Korea.

Chapter 7. Discussion and Conclusions

This chapter will be used to summarise the above discussion, focusing on similarities and differences of carers' attitudes in Scotland and Korea in terms of culture and institution. In addition, the findings and implications of this thesis will be discussed and the limitations of this study will be examined. Lastly, this part will present suggestions for further research.

7.1 Summary: Carers' Attitudes and their Origin

Scotland and Korea face the same social problems, such as an ageing population, an increase in social services and health services budgets, etc. Dementia care involves complicated social risks. Each country has approached and treated dementia and dementia care in a different way and different welfare policies affect carers' attitudes. Furthermore, each country has a different culture, and there are distinct differences in culture between the West and East. Previous studies have explained different carers' attitudes in the West and East through cultural variations. Scotland, as a Western society, has a highly developed

sense of individualism, while Korea has Confucianism which emphasizes family and filial piety.

This study aimed to investigate carers' attitudes towards a diagnosis of dementia, family care, community care and residential care in Scotland and Korea, and examine the origin of different carers' attitudes in Scotland and Korea. The dominant argument between West and East in previous comparative studies on attitudes was that culture made the difference. On the contrary, this study has asserted that Confucianism is a much less significant factor than differences in social policy.

In order to develop this argument, this thesis has carried out interviews with 14 Scottish carers and 28 Korean carers. Based on this data, it has examined carers' attitudes towards the diagnosis of dementia (chapter 3), family care (chapter 4), community care (chapter 5), and residential care (chapter 6). Each chapter analysed similarities and differences in attitudes in Scotland and Korea from the point of view of culture or the social welfare system.

Dementia Diagnosis

Diagnosis of the disease is the barometer of the social control and treatment system. People may experience a disease rather differently, although they have the same disease. Differences in understanding a disease, especially dementia, often stem from social institutions and

culture. Moreover, different social institutions and cultures may result in different interpretations and responses to a disease. This study, therefore, analysed the diagnosis of dementia in chapter 3, from the perception of social institutions and culture.

Chapter 3 explored the discovery of dementia symptoms, diagnosis of dementia and treatment. It found that carers' attitudes in Scotland and Korea were very different in each section. Firstly, Scottish carers felt dementia symptoms were "abnormal" while Korean carers felt dementia symptoms were "normal ageing". Secondly, older people with dementia in Scotland had a diagnosis in the early stage while people in Korea had their diagnosis delayed until the moderate or severe stage. Thirdly, Scottish carers, unlike Korean carers, highlighted the importance of anti-dementia medicine.

Regarding the discovery of dementia symptoms, Scottish carers considered these to be atypical, unlike Korean carers who saw them as part of the normal ageing process. Previous studies show that this phenomenon is presented according to cultural beliefs (Corner & Bond, 2004; Lee et al., 2009).

However, this study found that different attitudes in Scotland and Korea were a consequence of a lack of knowledge and public policy. In fact, there was an agreement that dementia was a normal part of ageing until the 1970s and 1980s among Anglo-Americans, and it was categorised as abnormal in ageing, only becoming a policy issue in the 1980s (Innes, 2009:8). The change in attitudes towards

dementia symptoms were affected by the Alzheimer Society's actions and campaigns (Downs, 2000). Moreover, these campaigns and actions influenced social policy and made public awareness of dementia significant (Alzheimer Scotland, 2006). Therefore, these social political movements have changed the attitudes towards dementia symptoms.

Meanwhile, Scottish carers and Korean carers did not attach strong stigma to dementia. Previous studies stated that Asian carers did so because they felt shame about the symptoms of dementia, which is recognised as a mental illness (Phillips, 1993; Hinton et al., 2000). However, only one Korean carer in my sample said that his family hid his mother's dementia, but he got advice regarding its diagnosis from his neighbour. Other carers mentioned that they discussed the signs of dementia with their friends or neighbours. This shows there is only a weak stigma attached to dementia in Korea.

In conclusion, the different levels of awareness regarding dementia symptoms are rooted in social policy rather than culture.

Regarding diagnosis, Scottish older people with dementia have been diagnosed earlier than those in Korea. The cultural approach explained a late diagnosis by stating that Korean carers feel shame about a dementia diagnosis because they 'lose face'. In fact, most Korean carers in this study did not feel shame about a diagnosis of dementia, but they had noticed dementia in relatively late stages and had to pay expensive medical consultation fees for a diagnosis. For

example, several carers mentioned that their relatives were diagnosed with dementia in order to use social care services. Some carers noticed that their relatives had dementia, but they did not think that they should be diagnosed. Kim's study (2002) also demonstrated a similar tendency and highlighted the lack of knowledge on dementia as a main reason behind late diagnoses in Korea. There, the average income of a family with older people with dementia was the equivalent of around 720 pounds per month in 1997. The monthly expenditure on health care averaged 79 pounds, but more than half of the families with older people with dementia were not spending on health care for dementia treatment or care (Kim, 1998).

This study also investigated the influence of a LTCI pilot scheme in Suwon. In point of fact, the scheme does not cover a diagnosis of dementia and coverage is limited for those with moderate or severe dementia. Thus, carers in Suwon did not receive a diagnosis of dementia earlier than those in Seoul. Likewise, this delay of diagnosis in Korea is related to the accessibility of health services and a lack of public information on dementia, rather than to 'face saving'.

In the case of treatment, Scottish carers had a strong willingness to use anti-dementia medicine compared with their Korean counterparts. These different attitudes originated from a lack of knowledge and affordability. For example, Korean carers believe that dementia has no cure, thus medicine is useless, while Scottish carers think the medicine helps slow down the progression of dementia and

its symptoms. This study found that when doctors provide a description of useful medicine then carers change their attitudes towards medicine in Korea. Moreover, it shows that the out-of-pocket charge of medicine has an influence on the low treatment of dementia in Korea. The case of Mrs. H1 highlighted the fact that if free medicine was available they would be keen to take it for their relatives. However, Scottish carers were provided with free medicine and consultations, therefore they had a higher accessibility and no issues of affordability to contend with. Moreover, Scottish carers were very actively pushed to get free medicine because they recognised it as a social right. Accordingly, the cultural difference is not a significant factor in the treatment of dementia among carers.

Previous studies explained that attitudes towards dementia and diagnosis differ between the West and the East, and that the differences originated from culture rather than social policy (Downs, 2000; Phillips, 1993; Hinton *et al.*, 2000). On the other hand, the institutional approach explained that the diagnosis of disease relates to health policy and systems, and in particular, accessibility and a lack of knowledge affect attitudes. This study found that carers' attitudes were different on the understanding, diagnosis and treatment of dementia between Scotland and Korea. Furthermore, it found that social policy was a more significant factor than culture in different carers' attitudes.

Family Care

The care of older people with dementia is mostly provided by their families. Moreover, family care is a significant factor in keeping older people with dementia at home (Alzheimer Scotland, 2008). Chapter 4 focused on family care at home in Scotland and Korea. Family care is a crucial demonstration of the differences in carers' attitudes in Scotland and Korea. I have identified five parts to this - living arrangements, family networks, family income support, carers' burdens and motivations. This study found similarities and differences in family care between Scotland and Korea. The similarities were found in motivation, family care (apart from family income support), and cognitive care, while differences were found in living arrangements, family networks, family income support, and carers' burdens.

Motivations were expected to be dissimilar in the two countries. Nonetheless, the phenomenon of motivation is very much the same in Scotland and Korea. Spouses tended to say love and affection was their motivation, while adult children tended to mention obligation and repayment in both countries. The motivation of a caring family member is not a distinct phenomenon in Confucianism, but it is rather an ethical issue. Every culture has familialism, even liberalism and conservatism emphasise family care, thus familialism in Confucianism is not unique.

In the case of family care, family carers in Scotland and Korea provided the most practical care for their relatives with dementia, such as personal care, preparing meals, cleaning and washing, etc.

In the case of living arrangements, most Korean carers in this study lived with their relatives with dementia while many Scottish carers, especially adult children, lived apart from their relatives but at a very close distance. However, the origin of this fact could be explained by social reasons rather than cultural reasons. Firstly, older people with dementia in Korea did not have their own house or inherit a house from their adult children, and as a result they lived with their children. Moreover, their adult children had jobs in the city, but older people with dementia lived in rural areas or in different cities; thus, older people with dementia moved into carers' homes. Furthermore, older people with dementia received few services, therefore, they could not stay on their own. This is a crucial fact that affects living arrangements. In fact, some Scottish carers moved in with their relative with dementia or lived close by. Changing the environment affects dementia, therefore Scottish carers were concerned about moving in with their relatives, rather than moving their relatives into their own house. Accordingly, culture is not a very significant determinant regarding living arrangements.

The phenomenon of family networks reversed the cultural hypothesis in this study. Scottish carers ensured the regular participation of other family members while Korean carers rarely got

help from other family members. For example, twelve out of fourteen carers in Scotland receive other family help while only ten out of twenty-eight carers experience help in Korea, six in Seoul, four in Suwon. This means that strong family networks exist in Scotland but not in Korea. It shows that the culture of familialism under Confucianism is weak in Korea.

In the case of family care, differences were found in income support and cognitive care. Korean older people with dementia received more fiscal support from their family than their Scottish counterparts. This study illustrates that most older people with dementia in Korea have no regular income because of the late establishment of a national pension, and as a result they rely on family income. Older people who have a regular income are independent from family income in the Korean case. Thus, this income support results from the absence of a pension system rather than from Confucian culture. Kwon (2001) argued that this family income transfer may not be continued because of the growing public income transfer. Moreover, the amount of family income transfer was only pocket money, thus older people with dementia are very poor. In the case of cognitive care, emotional support was the same in Scotland and Korea. Nevertheless, the dignity of older people's opinions was different. For example, Scotland has a power of attorney system while Korea does not have the legal protection for the opinions of older people with dementia.

Finally, carers' burdens were relatively different between Scotland and Korea. The reasons behind distress were almost similar but Korean carers suffered a heavier burden than their Scottish counterparts. Previous studies show that the Confucian culture influenced the higher level of burden among Korean carers compared with America carers because of higher expectations of family care (Kim, 2001; Youn *et al.*, 1999). However, the heavy burden in Korea has resulted from less support from other family members and community care services.

These findings are consistent with institutional perceptions as an explanation for family care, rather than a cultural perception.

Community Care

According to Butterworth (1995), community care has an important role in keeping older people with dementia at home through supporting family carers:

‘The valuable role of services is to enable the caregiver to continue caring and to maintain the person with dementia at home if that is their choice. The unpaid caregiver is a valuable resource; it is essential, therefore, that they should feel supported and able to count on the

regularity and continuity of services' (Butterworth, 1995:129).

The starting point in supporting family care is informing people of the resources available to them. This is key 'to prolonging home-based care for the person' with dementia (Teel & Carson, 2003:42). Chapter 5 highlights the accessibility of information and services, and carers' attitudes towards the utilisation of community care services.

In the case of information, Scottish carers had easier access than Korean carers. Scottish older people with dementia, even in the early stages, had regular visits from district nurses, thus the carers could easily discuss problems or get help from those nurses. On the other hand, most Korean carers in Seoul researched community care information by themselves. Carers in Suwon who were entitled to the long-term care pilot scheme more easily received information compared with those in Seoul. However, the coverage of the scheme was limited; thus, the information was available for moderate or severe dementia sufferers, but not those in the initial stages of dementia. This demonstrates a higher accessibility of information in Scotland compared with Korea.

Scottish older people with dementia received more community services than their Korean counterparts. In fact, the majority of Scottish older people with dementia received more than two services while Korean older people in this study received at most only one

service. Even carers in Suwon received mostly one service or nothing. Moreover, Scottish older people with dementia received free personal services at home while their Korean counterparts only got free services based on a means test. Previous studies insist that the low utilisation of community services is due to Confucianism in Korea. However, this study found that Korean carers have a strong willingness to use community care services if they are available. Moreover, Korean carers stated that the fee charged for using community care was a barrier for older people with dementia. Accessibility and affordability affect different carers' attitudes towards the utilisation of community services in Scotland and Korea.

In the case of the evaluation of services, Scottish carers had a similarly positive evaluation in that community care provided relief and confidence for carers. They also had similar complaints about waiting times, the changing of formal carers and a lack of services. Nonetheless, Korean carers suffered a greater lack of services than their Scottish counterparts; for example, all carers in Scotland received services, while 5 of those in Seoul and Suwon had nothing.

There are differences in the evaluation of community care in Scotland and Korea. Korean carers highlighted charges in services and professionalism. Free community services in Korea are provided based on a means test. LTCI has out of pocket charges for using its services. Therefore, higher income groups in my sample use community services less than lower income groups in Korea. In fact,

community care services are available for high income and low income carers in Korea but middle income carers can be excluded by cost. Moreover, older people with dementia mostly depended on the carers' family income; thus, there is a low utilisation of community care in Korea. The professionalism of formal carers in Korea was an issue because carers did not feel that formal carers provided proper care for older people with dementia. One carer mentioned that a 'home helper came and mostly watched TV with my mother' for four hours. Korean home helpers are time-based, not task-based. Furthermore, carers expected special treatment for their older people with dementia but formal carers did not provide any programme or activities. Thus, there was an issue about professionalism. Korea also had an issue about a lack of aid facilities. Home helper services provide practical help but they are based on a one carer visiting system. However, there are many bedridden older people without special facilities, such as a hoist. This may cause hazards not only for formal carers but also for older people with dementia. On the other hand, Scottish carers highlighted the issue of a short time of care. Scotland's free personal care is provided based on tasks, and as a result, Scottish carers said they could not do other activities or have a break even if they received free personal care.

In a nutshell, there were different attitudes towards community care between Scottish carers and Korean carers. This study found that

differences were caused by different social policies rather than cultures.

Residential Care

‘There is no doubt that residential care may be the most appropriate and effective way of meeting the needs of someone with dementia and a service of choice’ (DH, 2009). However, carers’ attitudes are various towards the utilisation of residential care, depending on the culture and social policy. Chapter 6 examined carers’ attitudes towards residential care based on factors such as willingness to use residential care, stigma and the concern of other people, consciousness of social welfare, confidence in service quality, accessibility and affordability of services, all of which are important factors to investigate.

Scottish carers were less willing to use residential care, contrary to the cultural expectations. In fact, more Korean carers wanted to use residential care immediately. However, a lack of residential care delayed access to service in Korea. Moreover, carers who desperately wanted to use residential care stated that a lack of community care at home affected their willingness to use residential care. Korean carers were exhausted because of the heavy burden of care and carers in lower income brackets were stressed because of combining jobs and caring. On contracts, Scottish carers received

more than one service at home, day care and respite care, thus they had less of a burden and maintained their jobs while caring. It shows that social welfare systems have a significant influence on the willingness to use residential care.

In the case of stigma, the majority of Scottish carers and Korean carers in my sample do not feel any stigma about using residential care. An interesting point is that only two Korean carers mentioned that there was still stigma attached to residential care. This result is different from previous studies in Korea (Jeung et al., 2005; see chapter 6). Korean carers in my sample were prepared to justify using residential care, thus they had 'no stigma' attached to residential care. Moreover, the quality of services has improved, and as a result, they felt even less stigma.

One carer stated that she was concerned about what other families would think in Korea. It shows that there may still be a silent pressure not to use residential care among families in Korea. However, carers mentioned that filial piety was weaker in Korea and carers had been told to use residential care by their family members and neighbours. Therefore, carers were less aware of what other people thought than in the past.

The consciousness of social welfare influences the attitudes towards residential care. For example, Scottish carers felt that residential care should be free while Korean carers believed that residential care should not be free, but the cost shared with the state.

Scottish carers recognised residential care as a social right but Korean carers still thought that families should be responsible for paying for residential care because they believed social policy was a charity. Therefore, Scottish carers complained about co-payments for residential care which would result in the sale of their relative's house. However, Korean carers had not experienced state participation in the care of older people in the past; thus, they did not expect free residential care. Moreover, the Koreans felt gratitude in receiving social services and residential care, as opposed to it being a social right. This resulted in fewer complaints about services because they believe social services and residential care are charity.

Scottish carers have higher expectations of residential care. For example, they think about the autonomy, privacy and dignity of older people with dementia in care homes. On the other hand, Korean carers think only of practical care, especially those in the lower income bracket. Moreover, they believe that care homes provide better care compared to home because of poor house conditions and care environments at home. In fact, many residential care homes in Korea have groups of people in a room without the appropriate number of carers and programmes. In general, the condition of care homes in Scotland is better than in Korea. However, Scottish carers have more complaints about their services because their expectations are higher and they consider the services to be a social right. Moreover, Scottish carers have more care services at home, therefore they think home is a

better place for relatives and feel reluctant to use residential care and are not confident about the quality of the services.

Regarding access and affordability, Scottish carers complained that residential care should be free because of the NHS. Although older people with dementia have free personal and nursing care in Scotland, they are still charged a hotel fee which is expensive. Therefore, access is a barrier to the use of residential care for older people in Scotland. It shows a “lame” long-term care system in Scotland. Scottish carers received free personal and nursing care at home, thus they continued to keep their relatives at home as long as possible. On the other hand, those in the lower income brackets have free access to residential care in Scotland. However, some of them do not choose residential care because they want to keep their relatives at home. They, moreover, have a free package of services. Thus, they have a choice and an alternative way to live. By contrast, the accessibility and affordability of residential care is lower in Korea. It puts a higher burden on those in higher income brackets, and consequently they could not use residential care. In contrast, carers in lower income brackets have free access to services, thus they are eager to use residential care. Some of them said even if they wanted to keep their relatives at home, the lack of community care service makes them choose residential care. Access and affordability are major problems in utilising residential care in Korea.

In summary, the cultural aspect may still exist in Korea but it seems not to be as significant anymore. Moreover, cultural influences are weaker on carers' attitudes towards residential care in Korea. On the other hand, 9 Korean carers desperately needed to use residential care while none of the Scottish carers wanted to use it at present. The lack of community care services encouraged Korean carers to use residential care. In fact, only about 0.5 per cent of older people in Korea received home help care, day care or short-term care (SunWoo, 2001). Although Korean carers had a strong willingness to use residential care, the lack of residential care and affordability were barriers to using it. Accordingly, this study shows that social policy has a more significant impact than culture.

7.2 Findings and Discussion

The differences I found between carers' attitudes in Scotland and Korea are illustrated in the Figures below. In Scotland, early diagnoses, strong family networks, and sufficient community care help Scottish carers to work and care. It results in less of a burden of care and less willingness to use residential care in Scotland. In contrast, late diagnoses, and a lack of support from family and community care, resulted in Korean carers being unable to work and

care. It created a heavy burden on carers and consequently a strong willingness to use residential care in Korea. This study found differences of attitude in Scotland and Korea.

Firstly, Korean carers and older people with dementia from their own description in the interviews appeared poorer and unhappier compared with their Scottish counterparts. Secondly, Korean carers were treated as resources in the Korean social care system while Scottish carers were treated as co-clients. Thirdly, there is awareness of abusive behaviour due to the heavier burden of carers in Korea. Finally, Korean carers have a greater willingness to opt for residential care than their Scottish counterparts.

To begin with, the Korean carers' burden is higher than that of Scottish carers, thus Korean carers are less happy than their counterparts. In the meantime, Scottish carers and Korean carers in this study were both suffering from their relatives' disturbing behaviour, but Scottish carers had more support from medical and community services than Korean carers. Kim (2001) and Youn et al. (1999) also illustrated that Korean carers suffered more severe depression than their Western counterparts did. Those studies pointed out that familialism is the main reason for the emotional distress of Korean carers (Kim, 2001; Youn et al. 1999). On the other hand, Marriott et al. (2000) suggested that treatment of and activities for people with dementia diminished the burden of caring. This study

points to the root of Korean carers' burden in having less community care support and fewer family networks for long-term care.

Next, Korean carers were treated as resources in the Korean social care system while Scottish carers were treated as co-clients, according to Twigg's models (1989). For example, the Korean pilot long-term care scheme and present care service in 2007 assessed only the dependents' needs. There is no carers' allowance in Korea, while Scotland has carers' allowance and carers' needs assessment. The Korean social care system did not recognise the carers' needs and simply considered them as background. Twigg (1989) said that carers as a resources model provided residual and marginal services. It means that formal care would be a substitute for informal care. In fact, the Korean government emphasises family care and filial piety to avoid providing significant formal care.

Additionally, this study shows that lack of support could result in abusive behaviour by family carers. For example, Mrs. N2 mentioned that she used not to give her mother lunch due to her work. However, a home helper from a long-term care pilot scheme feeds her mother at lunch time now. Mrs. N2 neglected her mother because she was unable to provide lunch for her during working hours.

Miss N1 stated that her father, who had already died, used to hit her mother due to stress and the difficulty of caring for his wife alone. In fact, Korean carers suffered from a higher anxiety and burden due to lack of support, such as weak family network and

shortage of community care. Moreover, Mrs. G2 said that her family did not participate in any care for her mother-in-law. She could not speak nicely of her mother-in-law due to the excessive burden of care she felt.

Cooper et al. (2010) say that family carers who have distress and depression are more likely to abuse their care recipients. Previous studies showed that carers who had a shortage of informal and formal care support might be more likely to abuse their care recipients (Pritchard, 1999; Phillips et al., 2000). In the case of Mrs. N2's neglect of her mother, this stopped through service intervention. Mrs. G2's case illustrated that a lack of family support can increase the burden. Her distress led to verbal abuse against her mother-in-law. According to the cultural perspective, the family network should be stronger in Korea (Cho et al., 2004) but in fact the Korean family network was weaker than that of Scottish families. It shows that the culture is less significant than institutions to understanding Korean carers' burden.

As seen above, there are abuses such as neglect, and physical and verbal abuse in Korean sample. However, these carers do not think of their behaviour as abusive. They referred to this phenomenon by way of describing the difficulties and burdens associated with care. In fact, abuse of older people is less recognized in Korea. For example, 41 per cent of formal carers among 414 in a survey said that they did

not know of elderly abuse (Yunhapnews, 2008). Therefore, carers in Korea were not aware of their abusive behaviour.

Last but not least, residential care is preferred in Korea more than in Scotland, as can be seen in Figures 7-1 and 7-2. For Koreans, this phenomenon may be very strange because it has been expected that Koreans (under Confucianism and filial responsibility) take care of their parents and relatives in their own home rather than in a facility. Kim (2002) insisted that filial obligation is the reason for the low preference for residential care in Korea. However, the phenomenon in this study reverses the cultural assumption.

According to research, a strong determinant of the use of residential care is a higher level of carers' burden (Banerjee et al. 2003; Black & Almeida, 2004). Korean carers prefer to use residential care due to the heavy burden of care. This finding is in agreement with the argument from Banerjee et al. (2003), and Black and Almeida (2004). In Scotland, early diagnoses, stronger family networks, and the potential for community care help Scottish carers to work and care. It contributes to a lessening of the burden of care and is relevant to the consideration of using residential care in Scotland. In contrast, late diagnoses, and a lack of support from family and community care, tended to result in Korean carers being unable to work and care. It created a heavy burden on carers and consequently a greater willingness to use residential care in Korea.

What is more, there are more older people with severe dementia in my sample in Korea (3 in Scotland; 5 in Seoul, 7 in Suwon). On the other hand, the period since symptoms were noticed was longer in Scotland than in Korea (7.1 years in Scotland; 6.1 years in Seoul; 6 years in Suwon); and the period since diagnosis of dementia was longer in Scotland than in Korea (6.9 years in Scotland; 2.7 years in Seoul; 1.8 years in Suwon). It can be surmised that Korean carers in my sample tended to recognise and diagnosis dementia later, and that as a result there would be faster development in the severity of dementia. Thus, Korean carers in my sample were experiencing a heavier burden of caring for older people with dementia.

Although earlier entry to residential care was possible due to availability of residential care in Scotland, the evidence from my sample shows that care services at home and community care help to delay the entry to residential care or less willingness to use residential care. Therefore, the higher willingness in Korea and a greater reluctance in Scotland to utilise residential care, are associated with institutional factors rather than culture.

Figure 7- 1 Carers' Attitudes in Scotland

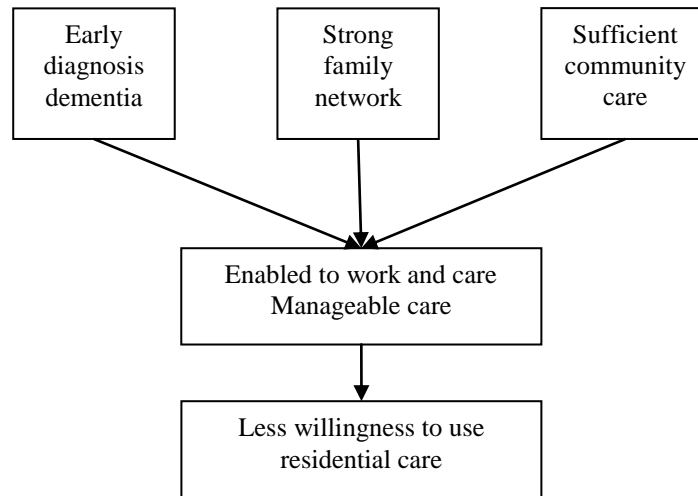
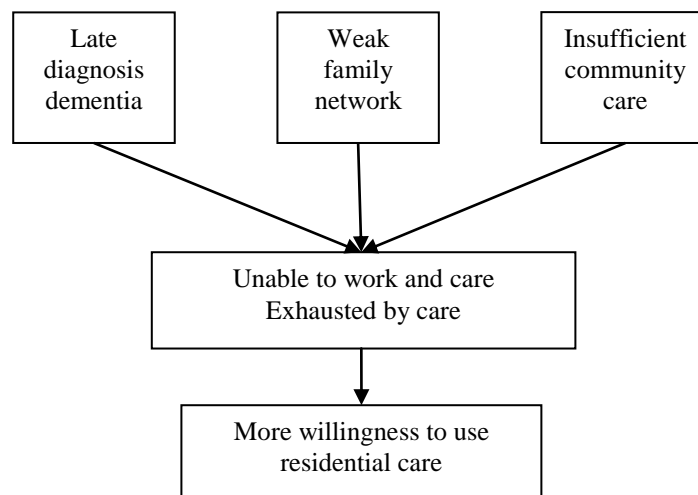


Figure 7- 2 Carers' Attitudes in Korea



What do the above findings mean? The origin of carers' attitudes in this study is the social policy context rather than the cultural one. In other words, the Korean carers' attitudes and behaviour towards diagnosis and long-term care services are a response to the residual

welfare system rather than Confucianism. This is contrary to the assertion of most previous studies that the cultural influence of Confucianism is the most significant factor behind families not using formal care services in Korea (Chee & Lewkoff, 2001; Jones et al., 2006; Lee et al., 2010; Kim, 2002; Park et al., 2004). However, this study found that Confucianism has a less significant influence than social policy on carers' attitudes towards the utilisation of health care, community care and residential care. It demonstrates that institutions such as social policy are a more significant factor than culture when explaining Korean carers' attitudes and behaviour.

Filial duty exists in Scotland as well as Korea. This may go against common assumptions about individualism in the West, while Korea as a part of the East is closely related to Confucianism and familianism. Korean carers' attitudes might change under modernisation and industrialisation, and the carers interviewed highlighted the limits of assumptions of filial piety derived from Confucianism.

In addition, this study found that the filial piety concept not only existed in Korea but also in Scotland. The dominant motivations of family carers are repayment and obligation, and family carers provide most care, such as cooking, washing, dressing, bathing and emotional support, in both countries. Hun and Chou (2000) argued that family care in Western society is less common than family care in

East Asian society. In contrast, I found a similarity between family care in Scotland and family care in Korea.

This finding supports Pung's (2007) argument that filial piety is not a unique value of Asian culture. In conclusion, the emphasis on cultural perspectives within Asian studies should be reviewed and institutional explanations might provide a more authentic understanding of Asian behaviour.

Secondly, the differences in diagnosing dementia, community care and family care in Scotland and Korea are rooted in social policy. Diagnosis of dementia is closely related to public health policy and access to health services as seen in the previous section (7.1 Summary). There are rarely cultural effects in the diagnosis of dementia. This finding is unlike previous studies which were based on cultural explanations (Philips, 1993; Hinton et al., 2000).

In the case of family care, Scottish carers receive more practical participation from other members of the family than Korean carers. From the cultural perspective, Korea has stronger familialism, but the family network was less strong than in Scotland in my sample.

On the other hand, Korean carers have higher cohabitation and income transfer rate with older people with dementia. Previously, this was explained by the factor of culture (Cho et al. 2004). However, most Korean carers live with their relatives for economic reasons. For example, older people with dementia do not have their own property and poor carers have to work and so are unable to move to relatives'

homes in different cities or rural areas. If older people in different cities receive enough community care then carers in Korea may not live together with their relatives with dementia.

In the case of family fiscal support, the Korean pension system was established in 1988 and expanded to cover all in 1999, so the older people in this study did not have a regular income from the state, requiring the family to provide income support for their relatives. Moreover, Kwon (2001) argued that family income transfer may become less significant as social benefits and pensions are introduced and matured. In fact, Mr. E1's mother received widow pension therefore his mother did not depend on him and his sibling financially. This shows that the social policy difference between Korea and Scotland influences differences in living arrangements and financial support.

With regard to community care, excepting residential services, Korean carers had less access to social services than Scottish carers due to differing levels of provision. This finding contrasts with previous studies, according to which Korean carers are less willing to use long-term care services because of filial piety (Choi, et al., 2002; Cha, 2004; Lee, 1995; Kim et al., 2002; Park et al., 2004). In reality, Korean carers mostly used only one service because of a lack of services and the out-of-pocket charges to which people in higher income brackets are liable. As written above, in the same context Korean carers prefer to use residential care. Accordingly, culture is a

less crucial aspect to understanding different attitudes between carers in Scotland and Korea.

Likewise, this study asserts that the residual welfare system is more persuasive than a cultural approach derived from Confucianism as an explanation for Korean carers' attitudes, unlike previous studies on East Asia, based on the cultural explanation. Moreover, this finding suggests that the Korean government use Confucianism as an excuse for not going beyond the residual welfare model.

7.3 Social Policy Implications

Some social policy implications arise from these findings. Early diagnosis and treatment can prevent costly involvement later (Geldmarcher, 2002). According to Knapp et al. (2007), the cost of the institutionalisation of older people with dementia is £7 billion per year in the UK. It is paid by the state (2/3) and older people and their families (1/3). Thus, the 'National Dementia Strategy' and 'National Priority' insist on the early diagnosis and early intervention in dementia to reduce institutionalisation. Gilley et al. (2004) argued that older people with behavioural disturbances, such as hallucinations and depression, result in higher risk of institutionalisation (Gilley et al. 2004: 1133). They also pointed out that 'these behaviour patterns are

potentially susceptible to therapy, efforts to modify or prevent them deserve careful consideration as a possible means to delay institutionalization for persons with AD (Alzheimer's disease).'

Mittleman et al. (2007) said that carer counselling and support at diagnosis can decrease institutionalisation by 28 per cent. Moreover, early diagnosis and intervention increases the quality life of older people with dementia and their carers (Banerjee et al. 2007; Mittelman, 2007). The late diagnosis of dementia and severe situation regarding dementia in Korea often leads to a strong willingness to use residential care. Therefore, the Korean government should offer public education on the early diagnosis of dementia promptly and extend free diagnoses for older people. Although the Minister of Health, Welfare and Family Affairs declared the 'General Plan for Dementia' in 2008, including a free diagnosis, this does not include the charge for an MRI or CT which is needed for an accurate diagnosis and to claim free medicine vouchers for those in low-income brackets (MHWFA, 2008). Likewise, the 'General Plan for Dementia' does not cover an accurate diagnosis. Therefore, the plan may not significantly improve the issue of early diagnoses due to the charge for an accurate diagnosis. If it is true that early diagnoses and treatment economically benefit a long term policy, the Korean government should provide a better offer for the diagnosis of dementia and treatment.

In Scotland, the GP role is significant in the early diagnosis of dementia. Therefore, GPs should be educated and trained to spot

dementia at an early stage. Moreover, GPs or doctors and other professionals in the area also have an important role in providing information services for dementia sufferers and carers. They should provide comprehensive information for older people with dementia and their carers.

A lack of community care services may result in early institutionalisation. The purpose of community care is to keep older people with dementia in the community as long as possible. Residential care requires ‘the highest amount of resources’ to care for older people with dementia (Wolstenholme et al., 2002). Therefore, community care is economically beneficial for the government³⁹. However, inadequate community care generates a strong willingness towards the utilisation of residential care in Korea. Community care should be developed based on needs, but the services in Korea seem to be fixed. Community care should provide tailored services according to the needs of carers and older people with dementia. Thus, community care would help to delay institutionalisation.

Furthermore, LTCI should have the coverage extended. Long-term care requires a higher degree of disability and long-term illness, thus it is limited to moderate or severe dementia. Some commentators said that this system encouraged older people to pretend to be ill to

³⁹ For example, the annual cost per person in community is cheaper than their counterpart in care homes as below (Knapp et al. 2007: 9);

- People in the community with mild dementia - £14,540
- People in the community with moderate dementia - £20,355
- People in the community with severe dementia - £28,527
- People in care homes - £31,263.

enable them to receive the services due to the limited coverage. Therefore, the coverage could be extended.

Moreover, time-based services could result in the inefficiency of long-term care in Korea. Time-based home help services in Korea make it seem as if there is a day care centre in every client's house. It is better to provide more day care centres for dementia and provide task-based home help services in Korea. This would be a more efficient use of resources.

There are risks in the work environment for formal carers in Korea due to a lack of facilities and a lack of staff. In the home help service, only one formal carer visits a clients' house. This may result in hazards for a formal carer and older people with dementia. This study found that many bedridden older people received the home help service, but a one-formal-carer-visiting system could not care for older people properly without any facilities. It could result in injury, not only for the carer but also for the older people. In this environment, Mrs. D1's mother in Korea stayed in bed all day while Mr. H's wife, with a similar condition, was hoisted up in the morning, sat in a chair for the day, then went to bed in the evening in Scotland. The quality of life for older people with dementia in Korea is neglected by a lack of aid facilities and staff. Long term care insurance in Korea should cover the issue and provide more aid facilities and transform the home help service.

On the other hand, Scottish carers required more time with home help services. It could be a good idea to take a lesson from Korea on home help services. The long term care in Korea and Scotland should provide choices for carers on whether they need time-based care or task-based care.

The dignity of older people with dementia is important. However, there is ignorance regarding legal provisions for older people with dementia in Korea. In Scotland, the Adults with Incapacity (Scotland) Act 2000 introduced provisions for substitute decision-making to protect people with incapacity through financial and welfare guardianship. The Adult Support and Protection (Scotland) Act was enacted in 2007 and implemented in 2008 to protect adults at risk of harm and potentially provides for assessment and short-term interventions whilst guardianship measures are sought. Power of Attorney (for Adults with Incapacity) in Scotland, if taken at an early point of diagnosis, gives individuals in the early stages of dementia some control and choice over who makes decisions on their behalf as the illness progresses. This system should be considered in Korea to protect the dignity of older people with dementia.

Moreover, abuse issues should be taken seriously in Korea. Pressured family care environments may lead to abuse or harm to older people with dementia, but there is no strong legal protection system in place as yet in Korea. In 2004, the Law of Older People Welfare introduced the provision of abuse of older people. The law

has a principle by which, if family victims do not agree to punish their family assailants, then the law cannot punish those assailants. Last year, there were 2,674 cases of abuse but only 2 cases were punished according to the Law of Older People Welfare (Yunhapnews, 2010). This shows the law is invalid for protecting abused older people.

Existing studies in the UK show that older people with dementia are frequently abused (Cooper et al. 2006; Cooper et al., 2008). According to Cooper et al. (2009), over half of family carers reported some abusive behaviour. The abusive actions are likely to be reported among family carers who suffer anxiety and depression (Cooper, et al. 2010). Moreover, greater time spent caring is linked with abusive behaviour (ibid.). A Korean study also shows that adult children, who were living with parents with dementia, tended to report abusive behaviour towards their parents (Oh et al. 2005). Carers' abuse is related to symptoms of dementia (Cooper et al., 2010). Therefore, reducing the time spent caring, and developing strategies of caring and treatment to reduce the dementia symptoms, may help to reduce abusive behaviour of family carers. Moreover, practical support may also prevent neglect and abusive behaviour, for example Mrs. J2's case which is mentioned in the findings and discussion section (see 7.2 Findings and Discussion).

The Adult Support and Protection Act in Scotland provides stronger protection than the law in Korean. In fact, authorities can investigate when they are suspicious that an adult is at risk of harm

according to the Act in Scotland. They take action and support to ensure the safety of the adult at risk. Authorities can take out banning orders to the person who may be causing abuse when authorities feel suspicions. Moreover, if the abuse is proved then the person who engages in abusive behaviour will get punished, without agreement with the older person at risk. Scotland's government advertised the Adult Support and Protection Act on TV to increase public understanding. Korea's government should provide a strong protection law for older people at risk and publicise the problems of abuse.

Regarding residential care in Korea, the quality of services should be investigated. Carers in Korea made very positive evaluations on the quality of services in residential care. However, some residential care, especially the cheap kind, provides insufficient services. The researcher visited several residential care homes in Suwon and Seoul. Most residential care homes ignored the privacy of older people. There were no private rooms and showers, unlike in Scotland. Moreover, the researcher observed staff changing nappies for older people in open spaces in residential care. Furthermore, there is a safety issue for older people with dementia. Some residential care homes did not have any lock on the main door that could result in people with dementia going missing. In fact, several incidents have happened in residential care homes in Suwon and Seoul. In Scotland, some carers had experienced missing older people with dementia even though they had proper locks on the front door to prevent it. There

should be regular investigations into care homes' regulations, the quality of services, and ethical caring.

The sale-of-house policy threatened Scottish older people and their carers in my sample due to a misunderstanding of present policy and expensive residential care. In fact, the present policy has been transformed to provide some flexibility for older people and the carers' situation. For example, if an older person with dementia entered residential care while the spouse, who was over 65, lived in their house, then the local authority would exclude the house price in the financial assessment. Thus, older person with dementia could receive some sort of subsidy for hotel charges without having to sell their house. Moreover, house sale can be postponed because an older person could leave residential care. If the house is shared with their relatives who are under 65, then, the relatives can get some share in the ownership. This is considered in the financial assessment. Therefore, the Scottish government should improve public understanding or provide better offers of residential care.

Moreover, there was an issue regarding expensive residential care in Scotland and Korea. In Scotland, they pay hotel charges but not for personal and nursing care, while people in Korea pay 20 per cent of the residential care charge. Both countries could set an upper limit on the fee for residential care to reduce the expensive charges for residential care.

7.4 Limitations and Suggestions

The objective of this thesis was to explore the attitudes and behaviour of family carers in Scotland and Korea to make sure whether culture or institutions were more important in determining their attitudes. The result is to highlight the dominance of institutions rather than culture. This conclusion has to be limited to a generalisation, because the sample interviewed was very limited and small. Therefore, for a definite conclusion more comparative studies may be needed.

However, a reflection on this study can inform the development of policies in Scotland and Korea to improve dementia care. The samples are not extraordinary cases. Moreover, the findings are repeated within the interview data and offer an in-depth glimpse of family care for older people with dementia. In fact, it provides a high quality of data and a serious consideration of dementia care. Therefore, the findings could be generalised and dedicated to improving the social policy of dementia care in Scotland and Korea.

In addition, the interviews in this study are with people from very specific groups, family carers of older people with dementia living at home. It is not wise to generalise findings to other carers. This is because attitudes among carers of older people with dementia may not represent the general attitudes of family carers of all older people. Dementia is also a specific illness and much more difficult to

care for compared with other older people. It involves a mixture of problems, such as the ageing population problem, their economic problems, physical disability, mental health problems, etc.

In addition, there will be limitations regarding the translation of Korean into English. In particular, it is not easy to translate interviews with delicate shades of meaning.

By and large, the above limitations stem from the initial trial in this area, and may therefore be inevitable. This study seems to be the first comparative study between Scotland and Korea.

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APPENDICES

Appendix 1. Interview Pack

■ Letter for programme organiser



Hyun Sook Lee
Department of Social Policy
University of Edinburgh
10 Buccleuch Place, 4th floor
Edinburgh EH8 9LW
Tel. 0131 6** ****
Mobile. 07* **** ****
Email *****.com

April 2007

Dear Sir / Madam,

Re: Doctoral Research on the attitudes of family caregivers who care for older people with dementia towards residential care

My name is Hyun Sook Lee and I am a PhD student in Social policy at the University of Edinburgh. I am writing to ask for your help with a doctoral research that I am conducting. I am doing 'A comparative study on the attitudes of family caregivers who care for older people with dementia towards residential care in Scotland and Korea'.

I would like to know what difficulties they as a carer have, how they feel about the care they give, and what they feel about residential care etc. In order to research this area, I intend to carry out interviews with family carers of older people with dementia.

Research Design:

- **Method:** Semi-structured qualitative interview, recorded by tape recorder.
- **Interviewee:** 15 family carers of older people who have moderate or severe dementia, be at home, aged 75year or over.
- **Interview hour:** approximately one hour.
- **Place of interview:** it will take into account interviewee's convenience and comfort for example their home, any other venues of their choice.
- **Interview date and time:** it will be arranged by their preference.
- **Confidentiality:** All information is confidential and personal details about interviewee will remain anonymous. All data will be stored in a secure place, to which only the researcher will have access. The data will be destroyed, after the research is completed.

By passing on my letters for carer to the family carers who care older people with dementia, you will help me greatly and this research will hopefully help others in similar situations in the future, in Scotland and Korea. I know your time is precious but I would like be most grateful if you would delivery my letter the carers.

Thank you for your pay attention to my letter. Please do not hesitate to contact me, if you any question about my interviews or the study. I am looking forward to hearing from you soon.

Best wishes

Hyun Sook Lee



■ Letter for interviewee

Hyun Sook Lee
Department of Social Policy
University of Edinburgh
10 Buccleuch Place, 4th floor
Edinburgh EH8 9LW
Tel. 0131 6** ****
Mobile. 07* **** ****
Email *****.com

Dear Carer,

My name is Hyun Sook Lee and I am a PhD student in Social policy at the University of Edinburgh. I am writing to invite you to participate my doctoral research. I am doing 'A comparative study on the attitudes towards residential care of family caregivers of older people with dementia in Scotland and Korea'.

I was involved in Claremont Park Nursing home as a volunteer for a year and Northfield and Willowbrae Community Care for older people with dementia for three further years. Through these experiences, I found that the lives of older people with dementia and their family caregivers are different from Korea. This has, therefore, led to the formulation of the questions 'what are the attitudes towards residential care and why do the attitudes differ in Scotland and Korea?'

In order to research this area, I intend to conduct interviews with family carers of older people with dementia. I would like to know what difficulties you as a carer have, how you feel about the care you give, and what you feel about residential care etc. All information is confidential and your personal details will remain anonymous. The data will be stored in a secure place, to which only the researcher will have access. The data will be destroyed, after the research is completed.

The place of the interview will take into account your convenience and comfort for example, it could your home or any other venues of your choice. The day and time will be also arranged by your choice for example, day time, early evening etc. The interview will take approximately one hour. The interview will be recorded by tape recorder, if you agree.

By doing this interview, you will help me greatly and this research will hopefully help others in similar situations in the future, in Scotland and Korea. I know your time is precious but I would be most grateful if you would spend an hour with me.

I have enclosed a stamp and envelop with my address. If you would like to participate in my interview, you can send back the last page of this letter to me with your signature and contact number. Then, I will call you to arrange a time for an interview with you if you agree.

Thank you for your help! Please do not hesitate to contact me, if you have any questions or comments. I look forward to hearing from you soon.

Yours Sincerely,
Hyun Sook Lee



Hyun Sook Lee
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Please return this page with your signature and contact number in the envelope provided, if you would like to participate in this interview.

I would like to conduct interviews with family caregivers of the older people who

- have moderate or severe dementia
- are at home
- are 75 or over 75 years old

Name

Address

Post code

Contact Telephone Number.....

E-mail.....

I am happy for you to contact me to arrange in this interview.

Signature

Date.....

Any questions? Please phone Hyun Sook on 07* **** ****

Thanks



Hyun Sook Lee
Department of Social Policy
University of Edinburgh
10 Buccleuch Place, 4th floor
Edinburgh EH8 9LW
Tel. 0131 6** ****
Mobile. 07* **** ****
Email *****.com

Please return this page with your signature and contact number in the envelope provided, if you would like to participate in this interview.

I would like to conduct interviews with family caregivers of the older people who

- have moderate or severe dementia
- are at home
- are 75 or over 75 years old
- having savings or capital less than £12,500 (include property)

Name

Address

Post code

Contact Telephone Number.....

E-mail.....

I am happy for you to contact me to arrange in this interview.

Signature.....

Date.....

Any questions? Please phone Hyun Sook on 07* **** ****

Thanks

■ Interview Schedule

Section A. Introduction of interview

The interviewer will introduce what the research is about. You could ask any questions about the interview or any other point at anytime throughout the interview.

Interviewer will ask the key questions during the interview. The interview will be recorded if you are agree. If you would unhappy about any questions, then you do not have to answer them.

Section B. Information about family caregiver and older person with dementia

- Who do you care?
- Are you married?
- Are you working at the moment? What kind of job do you have?

Section C. Diagnosis of Dementia

- Could you tell me, when your relative develop dementia?
- What was the first sign of dementia?
- How did you feel when you first found the signs?
- What did you do after find the sign?
- When did you diagnosis of dementia? Could you tell me the process of diagnosis of dementia?
- What degree of dementia do your relative have? Could you tell me the present symptom of dementia?
- Does or did your relative take a medicine for dementia? How do you think about the medicine?

Section B. Family care

- Do you live with your relative? If not, where does your relative live then?
- What do you do for your relative with dementia? Ex) do you do dressing, washing, cooking etc?
- Do you do financial support for your relative? Does your relative have their personal income or receive any financial support from government or pension?
- Do you have power of attorney for their relative's finance or welfare?
- Do you receive any help from other family member?
- Could you tell me, the changed of your life since your relative develop dementia? Ex) give up their job, distress of caring, health or mental problem etc.
- Could you tell me, why do you caring your relative with

dementia? Ex) love, obligation etc.

Section C. Community care

- Could you tell me, what kind of community care does your relative use?
- How did you know the services? Ex) information and process of receive services
- What do you think about the community services?
- Are there any barriers to use community care services?

Section D. Residential Care

- Have you ever think about using residential care?
- How do you think about residential care?
- Why do/don't want to use residential care for your relatives? Ex) quality of care service, Fee of residential care, filial piety, other people' opinions etc
- Are there any barriers to use community care services?
- Could you tell me, who should responsible for residential care fee? ex) state, family etc

Section E. Closing the interview

- Is there more you want to tell me?
- How do you feel the interview
- May I contact you again to further questions or clarify certain point? If you are ok, how can I contact you?

Thank you very much for letting me interview you.

Appendix 2 Development of Social Policy for Older People in Korea

Division		Name of Scheme	Ministry*	Authoritarian (~1986)	Democratisation (1987~1996)	Economic crisis (1997~)
Social Insurance	Pension	Government Employees Pension	MGAS	-1960 enacted and enforced		
		Military Personnel Pension	MND	-1963 enacted and enforced		
		Private School Teachers and Staff Pension	MEST	-1973 enacted - 1975enforced		
		National Pension	MHWFA	-1973 enacted	-1988 enforced, a work place with more than 10 workers	-1999 expanded into all people
	Health Insurance	National Health Insurance	MHWFA	- 1963 enacted but not a compulsory insurance, - 1976 revised as a compulsory, a work place for more than 500 workers	-1989 expanded into all people	-1998 integrated management system of NHI Funds for wage earners with Funds for non wage earners
	Work Injury Insurance	Work Injury Compensation Insurance		- 1963 enacted -1964 enforced, a work place for more than 500 workers		- 2000 expanded into a work place for more than a worker

	Employment Insurance	Employment Insurance			-1993 enacted -1995 enforced, a work place for more than 30 workers	- 1998 expanded into a work place for more than a worker
	Long-Term Care Insurance	Long-Term Care Insurance	MHWFA			- 2007 enacted - 2008 enforced
Public Assistance	Income Security	National Basic Livelihood Security	MHWFA	-1961 Livelihood protection enacted		- 2000 replaced by National Basic Livelihood Security Law
	Medical Service	Medical Assistance	MHWFA	-1977 enacted		
Welfare Service for older people	Elderly Welfare	Elderly Welfare Law	MHWFA	-1981 enacted	-1988 major revision	-1997 major revision -2006 major revision

Note: * **MGAS**: Ministry of Government Administration and Security, **MND**: Ministry of National Defence, **MEST**: Ministry of Education, Science and Technology, **MHWFA**: Ministry for Health, Welfare and Family Affairs